



# REACH-OUT

A Support Group for Teens  
Living with Chronic Illness

## Program Manual *First Edition*

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# Table of Contents

<b>Introduction.....</b>	<b>1</b>
1. REACH-OUT: At a Glance .....	2
2. Relevant Research and Theory.....	2
3. Instructions for Use .....	5
4. Tips for Facilitators.....	5
<b>Sessions</b>	
<b>Session 1:</b> Getting to Know You and Group Rules.....	6–9
<b>Session 2:</b> Communication.....	10–12
<b>Session 3:</b> Understanding and Expressing Emotions – Coping with Illness.....	13–15
<b>Session 4:</b> Taking Time for You: Advocating for Yourself .....	16–17
<b>Session 5:</b> There Is an “I” in Family .....	18–19
<b>Session 6:</b> Healthy Relationships .....	20–22
<b>Session 7:</b> Intimacy in Relationships.....	23–24
<b>Session 8:</b> Gaining Mastery Over Health and Self.....	25–30
<b>Session 9:</b> Future Planning .....	31–32
<b>Session 10:</b> Celebration and Group Evaluation .....	33–34
<b>Appendices</b>	
<b>Appendix A:</b> REACH-OUT Waiver and Release .....	35
<b>Appendix B:</b> Sample Video and Photo Consent Forms.....	36–37
<b>Appendix C:</b> REACH-OUT Satisfaction Survey.....	38–39
<b>Appendix D:</b> How to Play Guesstures® .....	40
<b>Appendix E:</b> How to play Catch Phrase® .....	40
<b>Appendix F:</b> Names of Emotions (to place on Jenga® blocks) .....	41
<b>Appendix G:</b> How to play Jenga® .....	41
<b>Appendix H:</b> I Have Learned (Anonymous).....	42
<b>Appendix I:</b> Yoga Alternative Activities .....	43
<b>Appendix J:</b> Instructions for “Getting to Know You REACH/BINGO” .....	44
<b>Appendix K:</b> Sample Emergency Contact Card .....	45
<b>Appendix L:</b> Medical Summary Form.....	46
<b>Appendix M:</b> Setup for Session 9 Activity: SMART Hockey.....	47
<b>Appendix N:</b> Sample Participant Graduation Certificate.....	48
<b>Appendix O:</b> List of Materials Needed for REACH-OUT .....	49
<b>References .....</b>	<b>50</b>

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*\*Cover artwork and REACH-OUT logo created by and provided with permission from Nastasia Santana.*

## *Introduction*

**REACH-OUT (Rapport, Empowerment, Advocacy, Connections in Healthcare, and Optimal Understanding of Transition)** began in 2002 as a direct response to both the needs within The Children's Hospital of Philadelphia and at a national level for adolescent-specific support and education that is integrated into a comprehensive healthcare plan for teens suffering with chronic illness. This manual has been developed over many years of working with teens and young adults coping with a variety of chronic conditions and has been shaped by participant and provider feedback. The group has evolved since its inception and has drawn from clinically proven interventions to support the curriculum development and overall success of the group.

REACH-OUT incorporates several models of intervention including: adaptation/skills development, social support and psycho-educational paradigms. It is grounded in a strength-based social work perspective on stress and coping, and has been designed specifically with older adolescents and young adults as the primary participant population. Research indicates this population — young people facing life-altering illnesses at a crucial period of development both physically and emotionally — tends to be underserved and would benefit from additional support and education to gain mastery skills for healthy physical and emotional development.

This program offers age-appropriate education and fosters peer support and mentoring through educational and social activities designed to enhance communication and model healthy living skills. The curriculum incorporates activities that teach and demonstrate coping strategies, problem solving, communication and social skills, as well as self-care management techniques and other transition-related topics that facilitate seamless medical transition to adult services. Facilitators model positive communication styles, negotiation and self-advocacy among other needed life skills to encourage healthy development and allow for a smooth transition to adulthood. REACH-OUT is designed to help participants feel more in control of their bodies and the decisions they make in their lives.

The group is comprised of six to 12 participants ages 16 to 20. REACH-OUT meets weekly for 10 consecutive 2½-hour-long sessions and has been offered as many as three cycles per year. The program can be offered at a variable frequency based upon facilitator and participant availability. The facilitators have found that groups are best attended when they are run after school hours in the seasons when the weather enables easy travel. The program can be held in a nonclinical location, such as a conference room or large meeting space.

# 1 REACH-OUT: At a Glance

## Setting/Participants:

- Participants are patients at The Children's Hospital of Philadelphia and attend the program on an outpatient basis. Healthcare professionals in various community settings, such as schools, health centers or community recreational facilities, can replicate the program.
- Participants are referred by medical providers, parents and self-referral. Program advertisements are placed in inpatient play rooms and multiple general outpatient and sub-specialty clinics affiliated with The Children's Hospital of Philadelphia. REACH-OUT groups are also advertised on the Children's Hospital website, [www.chop.edu](http://www.chop.edu).
- The program is intended for adolescents and young adults 16 to 20 years old who have been diagnosed with a chronic health condition and do not have associated developmental delays. Diagnoses not eligible for inclusion include any that indicate decreased cognitive capacity or significant psychiatric disturbance.

## Program Goals:

- Gain mastery over self-care needs to help manage chronic illness
- Develop positive communication style and enhance life/social skills
- Improve coping skills and self-efficacy
- Create a safe environment for teens to share their concerns and develop supportive relationships with their peers
- Enhance independent living skills (effective communication skills, self-advocacy, and financial and future planning)
- Increase compliance with medical regimen
- Foster positive relationships between patients and providers
- Encourage community partnerships between local families and healthcare providers to improve health outcomes

# 2 Relevant Research and Theory

The prevalence of chronic conditions among adolescents in the United States is estimated to be between 7 percent and 15 percent, depending on the definition of chronic illness [Suris '04; Newacheck '94]. Chronic illness during adolescence represents an additional, synergistic stressor during this potentially tumultuous life-stage [Woodgate '98; O'Dougherty '90]. There are multiple reciprocal effects of chronic illness on healthy adolescent development that encompass physical, social and psychological domains [Suris '04; Michaud '04].

Physically, chronic illness often alters pubertal growth and development and, depending on the condition, the outward appearance of the adolescent. Teens living with chronic conditions experience not only the physical symptoms of



their illness, but also the discomfort and potential side effects of their medical treatment plans. Additionally, teens with a chronic condition must cope with additional anxiety over the loss of their physical integrity and possibly their lives, concerns not usually shared by healthy teens. Furthermore, teens with a chronic condition often become more aware of their bodies and have been shown to possess a more negative body image compared to their healthy peers [Suris '96a; Wolman '94b].

The REACH-OUT program offers teens with chronic illness a safe and confidential space to share their concerns about their physical condition, as well as discuss frustrations with tolerating multiple medications and surgical procedures. Participants readily share their fears and triumphs as they face the challenges of living lives of uncertainty that are often very different compared with their healthy peers. Participants learn ways to discuss functional limitations with friends and loved ones and develop mechanisms to deflect negative comments that can sometimes accompany misconceptions about their illness.

The REACH-OUT program offers teens with chronic illness a safe and confidential space to share their concerns about their physical condition, as well as discuss frustrations with tolerating multiple medications and surgical procedures.

The social consequences of having a chronic illness during adolescence are also multidimensional. Teens diagnosed with a chronic illness often experience increased reliance on parents at a time when healthy peers are experimenting with independence [Suris '04]. In turn, parents may become overprotective [Stevens '96]. There are increased lifestyle restrictions and activity limitations. The social integration into a peer group that occurs naturally during adolescence is potentially thwarted by chronic illness: Data exist that chronically ill teens not only have fewer friends in their social networks [Pacaud '07], but also less intimate relationships [Stevens '96] and tend to be more socially marginalized than their healthy peers [DiNapoli '02; Pless '93, Westborn '92a; Merlijn '03]. Studies have also shown that teens with a chronic illness, as compared to healthy peers, experience delays in achieving major developmental milestones [Stam '06; Seiffge-Krenke '98], have poorer educational qualifications and longer periods of unemployment as adults [Pless '93], and possess fewer career and education prospects after high school [Stevens '96; Miauton '03].

The psychological challenges of living with chronic illness can also be difficult to navigate. The fundamental psychological task of adolescence is the forging of a unique, individuated identity [Erikson '68]. Inherent to this process is the acquisition of a set of life skills which are necessary for the transition to adulthood. Coping strategies and overall adaptation to having a chronic illness can modulate the

**The REACH-OUT  
curriculum  
simultaneously  
addresses the  
social isolation  
often experienced  
by participants  
and addresses  
the normal  
familial conflicts  
that are often  
exacerbated  
by a youth's  
illness (Session 5).**

impact that an illness has on psychological well-being, which may explain why some youth seem to be well-adjusted despite having to deal with the added stressor of having a chronic condition during adolescence [LeBlanc '03]. Coping is an adaptive and dynamic process that attempts to manage the external and internal demands that are perceived as taxing [Lazarus and Folkman '84; Chesney '03].

Throughout the REACH-OUT curriculum, youth learn healthy coping strategies that they can actually practice during and beyond group sessions. Additionally, teens are taught to identify situations for which their basic coping skills may become exhausted and draw upon the enhanced coping skills and strategies that are better suited to address the identified stressor.

Many studies have been published that explore whether support group interventions can improve the psychological well-being of chronically ill youth. Support groups in general have been shown to reduce isolation, foster a sense of identity, bridge gaps in traditional services, nurture empowerment, and facilitate the giving and receiving of support [Schopler '93].

The REACH-OUT curriculum is based on research findings on many types of effective interventions to maximize overall benefits to participants. Each week, groups are structured around a particular theme, which enable youth to learn and practice skills to help them adjust to and manage their illness. Activities involve various stress management techniques that participants can use for symptom reduction. Activities also help group members work together to problem solve and learn ways to better manage their illnesses from one another. For example, one participant who often forgot to take prescribed medications learned from another youth that he could set an alarm on his cellphone, which would remind him to take his medications at regular intervals throughout the day. The second half of each session is focused on helping participants express and process feelings while engendering a sense of shared purpose and support. Facilitators are instrumental in assuring that the group stays on topic and that all communication is respectful and focused around participants' strengths.

The REACH-OUT curriculum simultaneously addresses the social isolation often experienced by participants and addresses the normal familial conflicts that are often exacerbated by a youth's illness (Session 5). Additionally, the curriculum helps facilitate discussion of personal topics such as intimacy and relationships (Session 6 and 7). Each session also allots unique time, titled "Check in/Check out," to process, giving participants the opportunity to discuss ways to disclose their illnesses to potential partners and communicate about challenging topics such as fertility and body image. During Session 9, group members formulate realistic short-term future goals and learn ways to anticipate and navigate obstacles, which may impede success. Engagement in group activities encourages participants to consider realistic career pathways and seek assistance when needed. The curriculum is designed to prepare participants for understanding and meeting the challenges of adulthood.

## 3 Instructions for Use

The curriculum is divided into 10 session topics, each addressing particular objectives. In the manual, there is a list of objectives, supplies, a preparation list enumerating things to prepare prior to each session, and a time schedule for activities. Detailed descriptions are provided for each of the activities on the schedule. Then, there is a suggested icebreaker designed to build rapport among group members. Icebreakers are generally short and require little preparation. This is followed by a summary of the game that will be played for approximately one hour. Each game addresses the objectives of the week. (The curriculum may direct the user to an appendix, which will explain the rules of the game.) This is followed by a short break, which provides a transition for group participants and the facilitators to refocus for the discussion that follows. This Check in/Check out part of the group allows for processing of the thoughts and feelings brought up by the week's topic. During Check in/Check out time, youth often bring up sensitive personal topics and facilitators must insure that total confidentiality is maintained. There is a list of all needed materials and supplies in Appendix O.

## 4 Tips for Facilitators

This program manual should be used as a curriculum guide for facilitators, but is not intended to substitute for clinical sensitivity and skills of active healthcare providers leading these sessions. It is suggested that facilitators have knowledge and experience providing clinical counseling to adolescents. While session activities and discussion questions are described in this manual, they should be implemented with flexibility, clinical sensitivity, and awareness of group dynamics, developmental levels and additional stressors which may lead a clinician to modify an activity for a specific group.

For example, the Human Knot icebreaker described in Session 2 involves physical activity that may not be possible for every participant given various physical limitations. A participant who uses a wheelchair can remain seated outside of the group and serve as the outside lead to guide the group to successful completion of the activity, while remaining an integral player of the game.

In the manual there is a designated time for dinner and icebreaker activities. While the provision of food generally yields a higher attendance, it is not a proven theory and is therefore not required. The order and timelines for activities, including breaks, can be modified; however, the timelines suggested have helped the original facilitators maintain optimal pacing that allows for dynamic engagement, meaningful discussion and successful transition to the next activity. In addition, groups are offered at times which are convenient for young adults in a place that is easy to reach by public transportation. Subway and bus tokens are provided as needed to overcome financial barriers to attendance. Facilitators have also found it is easier to recruit participants during the school year. The group is not offered during the winter months due to the travel limitations posed by inclement weather.

**Objectives:**

- Establish the group goals and model appropriate boundary-setting for the participants
- Develop “group rules” with participants and have all agree to comply with terms
- Build rapport among group members and encourage open communication and comfort with group facilitators
- Create a safe and supportive environment which enables patients to openly express thoughts, opinions, beliefs, challenges and feelings and encourages willingness to learn among members
- Begin to develop and foster cohesion among group members in order to establish trust with one another and group facilitators

**Supplies:**

- 100 lined 3×5-inch index cards
- two small empty cardboard boxes for game cards
- 22×28-inch poster paper
- easel
- colored markers

**Preparation:**

- Review instructions provided on Pages 7 – 8 regarding the activity “The Wind Moves” before the session
- Place a blank poster/sign in front of the room for the group rules

**Schedule:**

5 – 5:30 p.m.	Dinner and icebreaker
5:30 – 5:45 p.m.	Group rules
5:45 – 6:20 p.m.	Activity: The Wind Moves
6:20 – 6:25 p.m.	Break
6:25 – 7:25 p.m.	Check in/Check out
7:25 – 7:30 p.m.	Pack up and leave

**Tip** Group Rule Development, Ownership and Accountability

It is important for group participants to formulate the rules that members must abide by for each group session and optimal group functioning. In doing so, they are learning and practicing self-advocacy skills, which is one of the main goals of their work together. The rules help to establish trust and rapport among members. Additionally, at this stage, members are making a commitment to group participation. Group rules are meant to establish safety and create norms that will facilitate open sharing of thoughts and feelings and provide an environment of mutual support.



5 – 5:30 p.m.

### Dinner and icebreaker

- Say your name and one thing that people wouldn't know about you just by looking at you.
- Group members should also say the name of the person before them to help them learn everyone's names.

5:30 – 5:45 p.m. **Group rules**

Some examples of rules to include are:

- Expectations for attendance (e.g., group members cannot miss more than three of the 10 sessions unless they are out due to sickness).
- Confidentiality: Explain meaning (e.g., what is said in group stays in group). Also describe exceptions to confidentiality (e.g., safety concerns, abuse, and harm to self or others).
- Cellphones should be turned off or to vibrate so as not to interrupt activities.
- Group members can say “pass” if they are uncomfortable answering a question or talking about a particular topic.
- Treat others with respect (e.g., you may decide that cursing is OK, as long as it is not toward another group member).
- Determine rules about lateness (e.g., group members should be no more than 15 minutes late or ... maybe they have to clean up after the activity).
- Determine how reminder calls will be made (e.g., Will there be email reminders, phone calls or text reminders? Who will be responsible for these?).

Post the list of rules for a minimum of four weeks to remind the group members of them. The facilitators must enforce the rules so participants know what is expected of them.

5:45 – 6:20 p.m. **Activity: The Wind Moves**

**Summary:** The Wind Moves is a fun and interactive way of helping people get to know each other better. The activity helps the players identify the many commonalities and the relatively few differences between group members, helping allay reservations about participation and decreasing feelings of fear and isolation. The activity described below is a modified version from the original, “The Big Wind Blows” from [www.group-games.com](http://www.group-games.com). It is suggested you add your own questions (e.g., “anyone who is more than 6 feet tall”) to suit the characteristics of the particular group.

#### Instructions:

1. Ask participants to form a circle in the center of the room with their chairs.
2. Remove one chair from the circle and ask that participant to join the facilitator in the middle of the circle. The participant in the middle is now called “The Big Wind.”
3. Explain the game to the group. The participant in the middle of the circle is the lead player and will initiate the activity by selecting a note card from the box and reading it aloud to the group.
  - a. The card will have two sides. The first side reads, “The wind moves ...” and the other side will complete the sentence with a statement or phrase.
  - b. The participant (“Big Wind”) will read both sides of the card to initiate each turn.
4. Participants are instructed to listen to the statement.
5. If the statement applies to them, they must immediately stand up and change seats with another participant who also is standing. **Note:** The participant in the middle of the circle must also find a seat once the statement is read aloud.

6. After everyone has exchanged seats, there should be one participant remaining without a chair. This participant now becomes “The Big Wind” and selects a new note card from the box and reads the statement.
7. The game continues in this fashion until all the cards have been selected.

### Questions for “The Wind Moves” game:

For an added challenge:  
Include 10 blank “joker cards” (you can put pictures of jokers or whatever you like on these). If someone chooses a joker card, that person has to make up their own statement. These statements must be true about themselves, for example, “The wind moves anyone who has lived in another state.”

Also, feel free to add your own note cards that you feel will be beneficial to participants to learn about one another and help with group cohesion.

- The wind moves anyone who always takes her medications.
- The wind moves anyone who has friends who are having sex.
- The wind moves anyone who is in school.
- The wind moves anyone who has graduated from school.
- The wind moves anyone who has been in a fight.
- The wind moves anyone who has been kicked out of his house.
- The wind moves anyone who has been to a concert.
- The wind moves anyone who has told a lie that got her in trouble.
- The wind moves anyone who has gotten away with a lie.
- The wind moves anyone who plays a sport.
- The wind moves anyone who is not from Philly (or your hometown).
- The wind moves anyone who is currently in a romantic relationship.
- The wind moves anyone who likes the Eagles (or your home team).
- The wind moves anyone who has stayed overnight at the hospital.
- The wind moves anyone who has lied to his doctor about taking his medication.
- The wind moves anyone who hasn’t told her friends about her illness.
- The wind moves anyone who is afraid of dying.
- The wind moves anyone who knows someone who had an STI (sexually transmitted infection).
- The wind moves anyone who knows someone who has sold drugs.
- The wind moves anyone who knows someone who has been arrested.
- The wind moves anyone who has used a gun.
- The wind moves anyone who has been suspended.
- The wind moves anyone who has a driver’s license.
- The wind moves anyone who has more than one doctor appointment a month.
- The wind moves anyone who has side effects from medication.
- The wind moves anyone who never got to be a child.
- The wind moves anyone who smokes marijuana (pot, weed).
- The wind moves anyone who drinks alcohol.
- The wind moves anyone who stopped taking medication because it made him feel worse.
- The wind moves anyone who has felt sad about being sick.
- The wind moves anyone who has ever felt like hurting herself.
- The wind moves anyone who has lost a loved one.
- The wind moves anyone who knows what he wants to be in life.
- The wind moves anyone who has been fired from a job.
- The wind moves anyone who has cheated on a partner.

The wind moves anyone who has felt alone.  
The wind moves anyone who has a pet.  
The wind moves anyone who is able to keep a secret.  
The wind moves anyone who has secrets.  
The wind moves anyone who likes attention.  
The wind moves anyone who enjoys dancing.  
The wind moves anyone who is afraid of needles.  
The wind moves anyone who daydreams in school.  
The wind moves anyone who has ever felt unsafe in her neighborhood.  
The wind moves anyone who feels like nobody understands.  
The wind moves anyone who has felt pressured to do something he knew was wrong.  
The wind moves anyone who has felt guilty about something she said or did.  
The wind moves anyone who has been betrayed by a friend.  
The wind moves anyone who has a best friend.  
The wind moves anyone who has someone he feels comfortable talking to.  
The wind moves anyone who lives with both parents.  
The wind moves anyone who lives on her own.  
The wind moves anyone who pays his own bills.  
The wind moves anyone who knows how to budget money.  
The wind moves anyone who knows how to speak another language.  
The wind moves anyone who has her natural hair color.  
The wind moves anyone who has a hard time getting along with other people.  
The wind moves anyone who keeps a picture of loved ones in his wallet.  
The wind moves anyone who is self-conscious about the way she looks.  
The wind moves anyone who wants to change the way he acts.  
The wind moves anyone who has been in a car with someone who has driven drunk or high.

**6:20 – 6:25 p.m. Break**

Provide guidance on what to do/where to go during the break (e.g., directions to the restrooms).

**6:25 – 7:25 p.m. Check in/Check out**

- What was it like to do this activity? Did you feel exposed?
- Were you surprised by anything that was just shared?
- What do you hope to share in group?
- Which things were easy to stand up about, and which weren't?
- Why?
- On a scale of one to 10, how comfortable do you feel doing this activity, with one being the least comfortable and 10 being the most comfortable?

**7:25 – 7:30 p.m. Pack up and leave**

Remind the group about the next meeting date, time and location.

## Session 2 Communication

### Objectives:

- Participants will identify three different modes of communication: verbal, nonverbal and written.
- Participants will develop an increased understanding regarding communication misalignments (miscommunication, misinterpretation, tone, messaging and reading physical cues) and discuss potential implications of these occurrences, such as arguments, confusion or potential escalation to violence.
- Participants will develop and practice active listening skills and be able to accurately process and understand the intended message that is being sent.

### Supplies:

- prizes: can be nominal items, \$5 gift cards, water bottles, stuffed animals, nail polish, etc.
- Guesstures® game
- Catch Phrase® game (electronic version)
- three AAA batteries

### Preparation:

- Read instructions to Guesstures (see Appendix D) and Catch Phrase (see Appendix E).
- Make sure the Catch Phrase game has batteries.

**Note:** Facilitator(s) should ask group members to describe three different types of communication. They include:

- \* **Verbal communication**, which includes sounds, words, language and speaking.
  - Example: “What are the things that make you feel that way?”
- \* **Nonverbal communication**, which involves physical ways of communication, like tone of the voice, touch, smell and body motion. Creative and aesthetic non-verbal communication includes singing, music, dancing and sculpturing. Symbols and sign language are also included in nonverbal communication. Body language is a nonverbal way of communicating.
  - Example: (Body language) Facilitator talks about how happy he/she is to be leading the group while looking miserable and crossing his/her arms.
- \* **Written communication**, which is writing the words you want to communicate in letters or symbols. The written communication can be edited and amended many times before it is communicated to the second party to whom the communication is intended.
  - Examples: Email, texts, advertisements, magazine articles

Facilitator may want to discuss the importance of understanding that written communication is permanent and, therefore, should be done with care.



#### Schedule:

5 – 5:30 p.m.	Dinner and Icebreaker: Human Knot Game
5:30 – 6:30 p.m.	Activities: Guesstures® and Catch Phrase®
6:30 – 6:40 p.m.	Break
6:40 – 7:25 p.m.	Check in/Check out
7:25 – 7:30 p.m.	Pack up and leave

#### Tip

##### Transition Tip

Last week we talked about why some subjects are harder to discuss than others and the ways in which we can determine whether others understand what we are saying. Today, we will talk more about the different ways in which we communicate both verbally and nonverbally with each other. As we play the games today, try to think about which ways of communicating are most challenging and how we can assure that others are listening to and understanding what we are saying.

#### 5 – 5:30 p.m. Dinner and icebreaker: Human Knot Game

**Summary:** This features a good icebreaker or teambuilding activity for new people to learn to work together — in close physical proximity! The goal is to figure out how to untangle the human knot without letting go of hands. Objectives of this game include team building and communication, problem solving, and getting to know one another. Recommended number of people: seven to 200 (group sizes of 10 are ideal).

Instructions for the Human Knot:

1. Get at least three people (the more the better and more complex).
2. Everyone in the group should form a tight circle (shoulder-to-shoulder).
3. Each person reaches into the center of the circle and grabs a hand of a person standing across the circle (each person must hold hands with two different people).
4. Try to untangle, so everyone in the group is holding hands regularly in a circle. You cannot let go of one another's hands.

**Hint:** When the circle is formed, some people can be facing out and some facing in.

The game can also be modified to include a group competition by dividing the group into two smaller circles and allowing them to compete for the quickest time. This game typically takes 15 to 30 minutes to complete. You can impose a time limit if you wish to make the game more challenging.

Penalties can be assessed if a member of the team breaks the chain (by letting go of someone else's hand). Other modifications can include wearing a blindfold or competing in silence.

When the game is completed, the facilitators should ask:

- How well did the group work together?
- Did anyone emerge as group leaders? How?
- What strategies did your group adopt?
- How did it feel to solve the game?



**5:30 – 6:30 p.m. Activities: Guesstures® and Catch Phrase®**

Guesstures

- Act out the words.

Catch Phrase

- Use other words to get your team to say the word on the screen.

**6:30 – 6:40 p.m. Break**

Provide guidance on what to do/where to go during the break (e.g., directions to the restrooms).

**6:40 – 7:25 p.m. Check in/Check out**

- Which game was easier? Why?
- Is it ever easier to act things out rather than use words?
- Do you ever communicate to others without words? How?
- Do you ever have a hard time expressing yourself?
- What gets in the way?
- How can texting or written communication lead to misunderstanding?
- Has anyone taken something you said the wrong way?
- How do you know when people understand you?
- How do fights get started?
- What does fighting have to do with communication?
- How does it feel to be misunderstood?
- How can this be avoided?

**7:25 – 7:30 p.m. Pack up and leave**

Remind the group about the next meeting date, time and location.

## Objectives:

- Participants will be able to identify and express their feelings about living with a chronic illness.
- Participants will identify various ways their illness affects their daily life.
- Participants will identify positive and negative coping techniques and strategies to manage stress.

## Supplies:

- 54 white 1x2<sup>5</sup>/<sub>8</sub>-inch labels (two sheets)
- Jenga® game
- three blank 3x5-inch index cards on which to write questions
- balloon air pump (not helium)
- permanent markers (12)
- three small packs of balloons – (15) red, (30) yellow and (15) blue

## Preparation:

- Blow up balloons.
- Read instructions to “If the stress doesn’t stop, my balloon will drop!” icebreaker.
- On each blank label, write the names of 54 different emotions (see Appendix F for examples). Place each label on one block from the Jenga® game.
- Read Jenga® instructions (see Appendix G).
- Facilitator should then write one of the following questions on three different index cards:
  1. How has your life has changed since your diagnosis?
  2. What are some things that you could do before that you are unable to do now? How do you deal with this?
  3. Has anyone ever made you regret that you disclosed information to them about your illness? What happened?



## Schedule:

5 – 5:45 p.m.	Dinner and icebreaker: If the stress doesn’t stop, my balloon will drop!
5:45 – 6:20 p.m.	Activity: Balance Challenge
6:20 – 6:30 p.m.	Break
6:30 – 7:25 p.m.	Check in/Check out
7:25 – 7:30 p.m.	Pack up and leave



### Transition Tip

Last week, we discussed communication and things that were difficult for us to express to one another. Often, some of the most difficult things to express or share with others are the most personal and private issues we face. In this group, we share the ongoing challenge of living with a chronic illness. One of the goals of this group is to share our feelings about what this is like and how we cope with our emotions and thoughts on a daily basis. As you will notice in today's icebreaker balloon activity, it can often be very hard to balance all of the responsibilities that we live with in addition to dealing with taking care of our illnesses. In doing this activity, try to think of ways in which caring for your illness impacts functioning in all of the areas of your life.

This activity is meant to demonstrate how each of the responsibilities in our lives poses additional challenges. Participants should be able to actually view how difficult it can be to stay in control of their lives regardless of how many challenges they face.

### 5 – 5:30 p.m. Dinner and icebreaker: If the stress doesn't stop, my balloon will drop!

1. Facilitators place all of the inflated balloons in the middle of the room.  
Each participant should receive a minimum of the following:  
**two yellow** – represents stressors  
**one red** – represents illness  
**one blue** – represents future goals
2. Ask participants to take a marker and label each yellow balloon with one of the stressors in their life (e.g., schoolwork, taking care of siblings, etc.).
3. Next, instruct each person to pick a red balloon and ask him/her to label it with the name(s) of his/her chronic illness(es).
4. Ask participants to label a blue balloon with one of their future goals (e.g., job, college, marriage).
5. Facilitators then ask participants to pick up their yellow “stressor balloons” and bring them over to another area of the room. Ask participants to keep the yellow balloons in the air by any means necessary. Let the group keep the yellow balloons in the air for 30 seconds before starting next step.
6. Facilitators should add in some of the blue “future goals” balloons and instruct the group to keep all their yellow and blue balloons in the air. It should be getting more challenging to keep the balloons in the air.
7. Next, add in the red balloons — one for each participant — and instruct her/him to make sure no balloon ever hits the ground. You can add in more yellow and blue balloons to keep the challenge going, but after about one minute the activity can be completed.
8. Instruct group to stop and only hold onto the balloons that are in the air. Observe how many balloons are on the floor, and ask the group about the challenges of keeping their balloons in the air. While participants are standing with the remaining balloons, ask the following:
  - How do you keep your focus with so much happening?
  - What things sometimes get in the way of reaching your goals?
  - Where does your illness fit in?
  - Did it help you to have others to share the responsibility of keeping the balloons in the air?
  - Does it help to share some of your burdens with others? In what ways?

#### 5:45 – 6:20 p.m. Activity: Balance Challenge

Depending on the size of the group, this game can also be played in teams. In this case, the player that causes the tower to tumble selects an index card and his/her entire team must answer the question.

Instruct all participants to sit around a table. Set up the previously labeled Jenga® blocks by placing them in rows of three, at right angles to the layer below, one on top of another to create a tower. One by one, participants take off one Jenga® block from a spot (other than from the top row) that they feel will not “unbalance” or tip over the Jenga® tower. They must then place the block back on the top level of the tower, building it higher. As they take a block, they must talk about:

- A time that they have felt the emotion labeled on the block or
- A situation that makes them feel the emotion labeled on the block

The person who knocks over the tower (the loser) must pick out one of the three index cards and answer the question on the card. The questions (written previously) are:

1. How has your life changed since your diagnosis?
2. What are some things that you could do before your diagnosis that you are unable to do now? How do you deal with this?
3. Has anyone ever made you regret that you disclosed information to him about your illness? What happened?

#### 6:20 – 6:30 p.m. Break

Provide guidance on what to do/where to go during the break (e.g., directions to the restrooms).

#### 6:30 – 7:25 p.m. Check in/Check out

- Did you realize that others sometimes feel similar emotions to yours in similar situations?
- Are there any emotions that are particularly difficult for you to express? Why?
- Are there some feelings (e.g., anger/sadness/hostility/frustration) that are not acceptable to express?
- How can the ways in which we express our feelings sometimes lead to misunderstandings?

#### 7:25 – 7:30 p.m. Pack up and leave

Remind the group about the next meeting date, time and location.

**Objectives:**

- Participants will learn and practice four healthy coping/self-care skills (pampering, journaling, poetry writing and yoga/exercise).
- Participants will learn to use journaling to express the impact their illnesses have on their lives.
- Participants will begin to think about short- and long-term life goals.

**Supplies:**

- one piece of 22x28-inch poster paper
- crayons, markers and colored pencils
- tape or glue
- yoga DVD
- DVD player
- journals with plain covers suitable for decorating, one per person
- decorations for journals (stickers/felt lettering/magazine cutouts, etc.)
- camera for photos
- makeup, nail polish and clean applicators
- copies of “I Have Learned” poem, one per person (see Appendix H)
- five pieces of blank paper for signs for activity station signs

You may want to enlist the help of additional staff members, a yoga instructor, a makeup artist and/or local salons to volunteer to lead the activities at the various “activity stations.”

**Preparation:**

- 1) Facilitators should create five different activity stations throughout the room and label each with the following headings:
  - Yoga/meditation station
  - “Write” time
  - Show ’em your poem
  - Relaxation/spa station
  - Glamour shot spot
- 2) In the space labeled “Yoga/meditation station,” set up the DVD player with yoga DVD (if you don’t have a live instructor). Leave space for participants to spread out and practice yoga and breathing exercises.
- 3) In the space marked “Write” time, place journals and decorations on a table.
- 4) Set up another station with copies of the “I Have Learned” poem (one per person) and the 22x28 poster paper. Label this “Show ’em your poem.”
- 5) Set up another station with makeup and nail polish, and label this “Relaxation/spa station.”
- 6) Set up the final station next to the relaxation/spa station, and label that “Glamour shot spot” and place the camera there.

**Schedule:**

- |                  |  |
|------------------|--|
| 5 – 5:15 p.m.    | Dinner and icebreaker: 2 Truths and a Lie® |
| 5:15 – 7:20 p.m. | Activity stations                          |
| 7:20 – 7:30 p.m. | Clean-up and leave                         |





### Transition Tip

Last week, we talked about illness and how it impacts us. Today, we will be doing some fun activities, which are good for your body and mind. While enjoying today's activities, please keep in mind that we are practicing these skills (writing in journals, making ourselves up, yoga and poetry writing) to help you take care of yourselves both physically and emotionally. Recognizing that living with a chronic illness can make life very stressful, we hope that you will use some of what you do today when you are feeling overwhelmed or frustrated by the challenges you face. Remember, these are activities that you can do alone or with friends/relatives.

5 – 5:15 p.m.

### Dinner and icebreaker: 2 Truths and a Lie®

Each participant shares two truths and a lie about themselves/their lives (but not in that order). Other participants try to figure out which statement is the lie. For example: A member of the group who had climbed to the top of Mount Everest and also played a sport at Penn State University, may say “I played basketball for Penn State, hiked Mt. Everest and took belly dancing classes.” The group would then need to decide which statement was the lie.

5:15 – 7:20 p.m.:

### Activity stations

Group facilitators will collect the journals and bring them back the following week. Facilitators should mention to participants that journals will remain confidential and securely stored for use in later week sessions.

**Yoga/meditation station:** If the facilitators can secure a DVD player, select a beginner/introductory level yoga and/or meditation DVD to guide the group activity. If this is not possible, then facilitators can either lead a guided imagery activity (see Appendix I) or a local yoga instructor can lead a short yoga exercise. The activity is intended to provide the group exposure to this type of activity.

**“Write” time:** Ask participants to decorate the front and back of their journals with words, pictures or drawings that represent and/or are important to them. Facilitate a discussion of how they choose to represent themselves. Ask each participant to create a “Dream List” of future goals, hopes and desires in their journal. (This will be referenced in Week 9.)

**Show ‘em your poem:** Make copies of the poem entitled, “I Have Learned” (see Appendix H). Ask each participant to read a line of the poem aloud. Ask participants to discuss which items they agree and disagree with and why. Next, participants should be asked to write one thing that they have learned in their life on the big piece of poster paper. By the end of the session, all participants will have contributed and authored a line of a unique group poem.

Facilitators can take the completed group poem and print it on sturdy paper and a frame and give it to participants at the final REACH-OUT session.

**Relaxation/spa station:** The activities at this station should be focused around making participants take time to prioritize their needs and develop a more positive image of themselves. For instance, a staff member may help to polish nails or a local makeup artist may volunteer to give makeup tips or help apply makeup to leave the group members feeling beautiful/handsome.

**Glamour shot spot:** An adult (facilitator or volunteer) can take photographs of the participants before and after their makeover. Take a group shot to be developed and given on the last night of group as a reminder of their good work. Pictures provided to the participants can be added to their journals.

7:20 – 7:30 p.m.

**Clean-up and leave** *Note: there is no Check in/Check out this week since the group is discussing the activities throughout the evening.*

**Objectives:**

- Participants will be able to identify family strengths and challenges, their role in the family, and the relationships between family members.
- Participants will identify non-family members (e.g., teachers, coaches, religious leaders, doctors, friends) for support if family members are unavailable and/or unable to provide needed support.
- Participants will learn how to engage in conversations with peers to normalize and validate family challenges that are experienced within all families.

**Supplies:**

- one 13.30-ounce bag of either M&M's or Starburst (or sugar-free colorful candy, if needed)
- markers
- 30 4x5-inch labels/name tags that can be taped or with adhesive on the back to attach to clothing

**Preparation:**

Lay the labels out on the table for participants to use to identify the roles of their family members. (See activity.) Read instructions to family sculpting activity listed below.

**Schedule:**

5 – 5:30 p.m.	Dinner and icebreaker Family Fiesta
5:30 – 6:30 p.m.	Activity: Family Sculpting
6:30 – 6:40 p.m.	Break
6:40 – 7:25 p.m.	Check in/Check out
7:25 – 7:30 p.m.	Pack up and leave

**Tip****Transition Tip**

Last week, we talked about coping and the importance of taking care of yourselves. Today, we are going to talk about how we can rely on other people to help us cope or care for our illness. Families can consist of people we live with, people we are close to and our relatives. Even though all of our families may look different, the behaviors and communication dynamics that exist are true for most of us. Sometimes, it is easier to talk to our friends, teachers and other adults than it is to our own families. Today, we will do an activity to help the group to see some of the benefits and challenges we face in our relationships with our family members. While you are doing the activity, try to think about what is the same/different about each of our families.

**5 – 5:30 p.m.****Dinner and icebreaker Family Fiesta**

- Instruct the group to take the bag of candy, and ask each participant to take as many pieces as they would like, but ask them not to eat any until the facilitator says it is OK.
- Once everyone has candy, ask participants to sort it into different piles by color.
- Once the candy is sorted, tell them what each color represents and ask each participant to say one thing about his/her family for each color M&M/Starburst they picked:

- **Green:** Talk about a family member who gets on your nerves.
- **Yellow:** Talk about a family member who intimidates you or makes you feel small.
- **Red:** Talk about a family member who makes you angry.
- **Blue:** Talk about a family member you go to for support.
- **Orange:** Talk about a family member who understands you.
- **Brown:** Talk about a family member whom you admire.

#### 5:30 – 6:30 p.m. **Activity: Family Sculpting**

The object of the family sculpting activity is to create an interesting portrayal of each person's role in his/her family as well as to help express the relationships of family members to one another. The job of the facilitator in this activity is to help participants depict accurate "sculptures" and show the group the similarities and differences between their families.

1. Facilitator picks a teen to create the first "family sculpture." This person will be referred to as "I." The "I" participant is instructed to identify three actors who he/she wants to be part of a story that they will share with the group.
2. The "I" then takes three labels and labels each "actor" with names of the roles he/she plays in the family. (e.g., mother, brother, cousin, etc.)
3. "I" is then encouraged to pose "sculptor actors" into various positions and simulate actions that would tell a story about their family. For example, if a family consists of three sisters and a mom, but the youngest sister is not very attached or involved with the family, the sculpture may show all four people, but have the younger sister further away from the rest of the group symbolizing the separation. The "I" (storyteller) should include him/herself in the pose/sculpture.
4. "I" should also tell each "actor" to engage in an action that is representative of what that person is often doing in the family. For instance, if the father is an alcoholic, he may be continually drinking from a bottle or stumbling around drunk.
5. When all of the actors are in position, the facilitator says "go" and the actors' role-play their parts in the sculpture for at least one minute. The facilitator then says, "Freeze," and all actors freeze in their respective spots.
6. The participants who are observing (those who are not the actors) discuss what they think is going on in the family sculpture.

The facilitator may ask questions of the group to try and elicit information such as:

- What is "I" trying to tell you about his/her family?
- What is each person's role in the family?
- Why might it be hard to connect with certain family members?
- "I" can then be asked to talk about his/her family dynamics and the role that he/she plays in the family.

#### 6:30 – 6:40 p.m. **Break**

#### 6:40 – 7:25 p.m. **Check in/Check out**

- How do you define family?
- What do our families mean to us?
- How are the issues in our families similar/different?
- How do our families shape our thoughts about others and ourselves?
- How does your family deal with your illness?
- Where else can you turn if you are not getting what you need from your family?

#### 7:25 – 7:30 p.m. **Pack up and leave**

**Objectives:**

- Participants will be able to identify characteristics of healthy and unhealthy relationships.
- Participants will learn how to have difficult conversations with their romantic/intimate partners. Topics may include: sexual health, illness and body image.
- Participants will develop the ability to recognize and minimize unhealthy relationship choices and practice effective communication skills to express needs and concerns with their partners.

**Supplies:**

- copies of “Getting to Know You REACH/BINGO” card (see Appendix J). One is required for each group member.
- large dry-erase board and erasable markers or chalkboard and chalk
- prizes (e.g., \$5 gift cards, movie tickets) for half of the total number of group members
- two buzzers or two bike horns
- pens

**Preparation:**

Facilitators should set up the room as shown in the diagram marked “Room Setup for Partner Password.” (See next page.)

Pass out REACH/BINGO cards and pens to all group participants. REACH/BINGO card template can be modified for specific group information.

Read instructions to Partner Password. (Game is loosely based on Family Feud®.)

**Schedule:**

5 – 5:30 p.m.	Dinner and Icebreaker: Getting to know you BINGO
5:30 – 7 p.m.	Activity: Partner Password
7 – 7:10 p.m.	Break
7:10 – 7:25 p.m.	Check in/Check out
7:25 – 7:30 p.m.	Pack up and leave

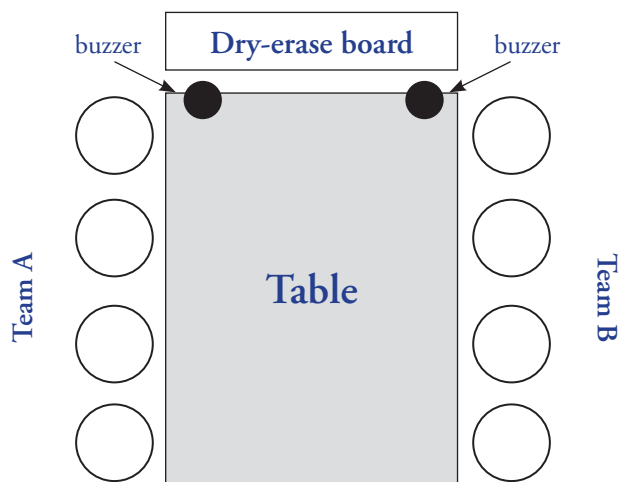
**5 – 5:30 p.m.****Dinner and icebreaker: Getting to know you REACH/BINGO**

(See Appendix J for instructions)

The object of the game is to get to know the group participants and to be the first player to complete a row, column or a diagonal line on the bingo board.

Continue the game to allow additional discussion among the group and award a prize to the first person to complete the entire REACH/BINGO board.

### Room Setup for Partner Password



Line up chairs along each long end of the table facing one another (See diagram above). Facilitator will remain at the head of the table with dry-erase or chalk board, which acts as the game board. Place the board in front of the group on the front table, and place a buzzer or horn on each side of the front board.

For each round, the facilitator must write the question on the game board and then leave blank numbered spaces for the answers. The facilitator then asks the first member of each team to come up to the front table and answer the questions on Page 22. The facilitator should write each answer on the board as the team identifies each one given below the question on Page 22. There will be six rounds.

### Instructions for Playing Partner Password

1. Divide the group into two equal teams (if possible).
2. One member of each team faces the other in a face-off. Each person is given a horn or buzzer. The facilitator reads the first question off the game board.
3. The team that buzzed or honked in with the correct answer which is closest to the top of the board receives control of the board and has the option of playing or passing control to the other team.
4. The team that has the control tries one by one to reveal all of the correct answers to the question before receiving three strikes. (If the answer is not on the board, the team gets one strike.)
5. If the team receives three strikes before getting all of the correct answers, control is passed to the other team.
6. The team that now has the control is able work together to come up with one answer in the hope that it is found on the board.
  - If it is, one point is added to the team's score.
  - If not, the other team gets the point.
7. Points are collected as each team finds its answers to the question on the board. (The facilitator keeps score.)
8. Continue the game, repeating steps two through seven.
9. Each team tries to collect the most points. There will be six rounds.
10. The team with the most points wins the game!

*\*Instructions adapted from Family Feud®*



### Partner Password Questions:

I) Name seven types of relationships. (7)

- |                                |   |
|--------------------------------|---|
| 1) Associates                  | 5) Hit it and quit it, jump on/jump off |
| 2) Friends                     | 6) Friends with benefits                |
| 3) Person you are “talking to” | 7) Boyfriend/girlfriend (boo)           |
| 4) Family                      |   |

II) What are your favorite things to do with a partner? (6)

- |                           |                                     |
|---------------------------|-------------------------------------|
| 1) Talk/text on the phone | 4) Go to the mall                   |
| 2) Watch movies           | 5) Play games                       |
| 3) Go out to eat          | 6) Get busy (hugging/kissing, etc.) |

III) What are the five most common sexually transmitted infections (STIs)? (5)

- |                        |                 |
|------------------------|-----------------|
| 1) HPV (genital warts) | 4) HSV (herpes) |
| 2) Chlamydia           | 5) Gonorrhea    |
| 3) Trichomoniasis      |                 |

IV) How do you know when to end a relationship? (9)

- |  |  |
|--|--|
| 1) Partner is threatening<br>you/emotional abuse | 5) Find out partner is cheating                    |
| 2) Arguing a lot                                 | 6) Frequent breakups                               |
| 3) Physical abuse                                | 7) Frequent sexually transmitted infections (STIs) |
| 4) Makes you feel bad                            | 8) Friend/family don't like him/her                |
|  | 9) You are no longer interested in your partner    |

V) What are some good qualities to look for in a partner? (7)

- |                        |                      |
|------------------------|----------------------|
| 1) Good personality    | 5) Fun               |
| 2) Trust               | 6) Similar interests |
| 3) Brains/intelligence | 7) Attractive        |
| 4) Respect             |                      |

VI) What ideally should happen before you consider sex with a partner? (9)

- |   |  |
|---|--|
| 1) Love/care                                  | 6) Discuss birth control/condom use                    |
| 2) Trust                                      | 7) Feel comfortable kissing/touching/<br>hugging, etc. |
| 3) Talk about sexual<br>history/past partners | 8) Check out private parts                             |
| 4) Talk about sex                             | 9) Get to know his/her family/introduce to yours       |
| 5) Get tested                                 |  |

**7 – 7:10 p.m. Break**

**7:10 – 7:25 p.m. Check in/Check out**

- How do you know you're in a healthy relationship?
- (Role-play) You just found out that your partner cheated on you and gave you chlamydia.
- What needs to happen in order for you to feel safe sharing about your illness?
- Are you uncomfortable talking about your illness with anyone? Why?
- When might you feel comfortable talking about your illness with friends or a partner?
- Is there someone you know now who you trust with this information?
- Are they helpful and respectful?

**7:25 – 7:30 p.m. Pack up and leave**

**Objectives:**

- Participants will identify indicators that allow them to feel comfortable with others in intimate relationships.
- Participants will understand and identify the differences between emotional and physical intimacy.
- Participants will learn about ways to prevent unplanned pregnancy and protect against sexually transmitted infections.
- Participants will play a word association game to examine the many ways in which ideas/objects/actions are discussed and then interpreted based on word choice.

**Supplies:**

- prizes: e.g., small gift cards, gloves, mugs, nail polish, etc.
- different colored 3x5-inch index cards
- large pad of 22x28-inch poster size paper and markers
- timer (three minutes) or stopwatch
- pens/markers

**Preparation:**

Facilitators should label each index card with one of the phrases below. Be sure to only place the phrase on the card, numbers should not be included.

- |                                |                                      |
|--------------------------------|--------------------------------------|
| 1. Meet the person             | 11. Meet their parent(s)/caretaker   |
| 2. Get to know them            | 12. Know what feels good for you     |
| 3. Exchange phone numbers      | 13. Talk about sex with your partner |
| 4. Earn their trust            | 14. Discuss comfort levels           |
| 5. Discuss previous experience | 15. Have protection                  |
| 6. Cuddle                      | 16. Foreplay                         |
| 7. Kiss                        | 17. Check out person's genitals      |
| 8. Meet their friends          | 18. Put on a condom                  |
| 9. Get tested together         | 19. Other types of sex               |
| 10. Discuss birth control      | 20. Sex                              |

Read the instructions to the game "What's that word?" listed below. Set up two 22x28 posters on the tables on opposite sides of the room

**Schedule:**

- |                  |                                   |
|------------------|-----------------------------------|
| 5 – 5:30 p.m.    | Dinner and icebreaker: Line It Up |
| 5:30 – 6:50 p.m. | Activity: What's that Word?       |
| 6:50 – 7 p.m.    | Break                             |
| 7 – 7:25 p.m.    | Check in/Check out                |
| 7:25 – 7:30 p.m. | Pack up and leave                 |



### Transition Tip

Last week, we talked about some aspects of healthy and unhealthy relationships and explored the differences between them. Today, we will focus specifically on intimacy and how this is expressed both through words and actions. The ways in which we talk about sex and the words that we use to describe it express many different meanings. Today, we will further explore those meanings.

#### 5 – 5:30 p.m. **Dinner and icebreaker: Line It Up**

Ask the group, “What should ideally happen before you decide to have sex?”

Give out the labeled index cards and ask the group to arrange them in the order that makes the most sense to them as a group. Encourage group discussion and problem solving. Once they have an agreed upon order, ask the group to discuss why they selected the order they did and compare it to “suggested” order on Page 23.

#### 5:30 – 6:50 p.m. **Activity: What’s that Word?**

1. Divide into two teams.
2. Both groups are given six 22x28-inch pieces of poster-size paper.
3. Facilitators state one word from the suggested word list below and instruct the teams to come up with as many words or phrases that are used to describe the given word. Each round is time limited to three minutes. Teams must work together and create a list containing as many words or phrases as possible within that time period. After the three minutes are over, the first team reads off its list and the facilitator writes the different words and phrases on the master list in the front of the room.
4. Once completed, the second team reads its list.
5. Any words that are duplicated are crossed off and any new ones are added to the list in a different color ink to keep track of which team suggested the words.
6. The team with the most unique (non-duplicated) words is the winner! Prizes are given to the winning team.

##### **Suggested word list:**

Sex	Vagina
Alcohol/drugs	Breasts
Fighting/violence	Sexually transmitted infections
Penis	

#### 6:50 – 7 p.m. **Break**

#### 7 – 7:25 p.m. **Check in/Check out**

- Do you feel that there is pressure to have sex?
- How comfortable are you disclosing the details of your illness to prospective partners?
- Do you know how to talk about sex with your partner?
- How do you bring up concerns ... like birth control, condoms or getting tested?
- Do you know what to do if you contract an STI (sexually transmitted infection)?
- Have you thought about/discussed with your doctor whether your illness or treatments might affect your fertility in the future?

#### 7:25 – 7:30 p.m. **Pack up and leave**

**Objectives:**

- Facilitators will reiterate the importance of developing positive coping skills and strategies.
- Participants will create medical summaries, emergency contact cards and duct tape wallets to encourage self advocacy and heighten sense of autonomy over healthcare and overall functioning.
- Participants will identify healthcare challenges and strategize effective methods to optimize the healthcare experience.

**Supplies:**

- art supplies (colored paper, markers, balloons, glue, etc.)
- colorful rolls of duct tape
- three 8x10-inch sheets of clear plastic cut into 4 ¼x2 ½-inch pieces (You need one piece per person.)
- emergency contact cards (see Appendix K)
- medical summary form (see Appendix L)
- crafting knife or sharp scissors (two or three for group to share)
- rulers (two or three for group to share)

A doctor, nurse practitioner or other healthcare provider should be invited to help participants complete their medical summaries and emergency contact cards.

**Preparation:**

1. Place one seat at the front of the room for the designated “Caller” for the Reverse Scavenger Hunt. Place another chair in the front of the room for the second facilitator who will act as the judge.
2. Set up two tables that are equidistant from the facilitators. One team will be seated at each table.
3. Divide the art supplies between the two tables.
4. Set up a fourth area of the room to be used for wallet-making.
5. Place the duct tape, crafting knives, scissors, 4 ¼x2 ½-inch clear plastic sheets and rulers in the wallet making area.

**Schedule:**

5 – 5:20 p.m.	Dinner and icebreaker: Reverse Scavenger Hunt
5:20 – 6:15 p.m.	Creating medical emergency cards and summaries
6:15 – 7:15 p.m.	Activity: Making duct tape ID holders
6:30 – 7:20 p.m.	Check in/Check out (Do at same time as duct tape ID activity)
7:20 – 7:25 p.m.	Break
7:25 – 7:30 p.m.	Pack up and leave



### Transition Tip

Last week, we talked about intimate/physical relationships and keeping ourselves safe. Today, we are discussing other ways that we can take care of ourselves, such as going to the doctor, taking needed medications and taking charge of our overall health. Sometimes, going to multiple doctor office and hospital visits, taking medications, and feeling “different” than other people can cause stress that people who don’t have these challenges can’t relate to. During this activity, try to think about ways you can decrease the stress of living with a chronic illness. Today, we will complete medical emergency cards and summaries, as well as make personalized duct tape wallets to carry our photo and medical ID cards in an effort to simplify and organize our important information and start to take personal responsibility for getting our healthcare needs met.

## 5 – 5:20 p.m. Dinner and icebreaker: Reverse Scavenger Hunt

- Divide the group into two teams.
- One facilitator is designated as the “caller,” and he/she will call an item from the list
- Assign a designated “runner” for each team. The runner is responsible for running the team answer/selected items to the judge for review and scoring. This person can change every turn in order for each player to have a chance to be a runner, but he/she must be selected prior to the start of the turn.
- The caller/facilitator will read the items, one at a time, from the list below.
- The other facilitator should judge which team gets the most creative and acceptable answer first. For example: When the caller asks for a picture of your pet, each team can draw one and present it to the caller.
- The team to get their runner to the caller with the best, most creative answer first gets a point.
- Whichever team gets the most points wins!

Item list:

- |   |  |
|---|--|
| • Medical card  | • Phone number to your doctor  |
| • Photo ID  | • Recite your medications while hopping on one foot                            |
| • Prescription  | • Sing the symptoms of a condition (facilitator names asthma, diabetes, ect.)  |
| • Emergency contact card                              | • Demonstrate the universal sign for choking                                   |
| • Emergency contacts listed by phone                  | • State three possible side effects of medication                              |
| • Picture of your pet                                 | • Name two chronic illnesses   |
| • Picture of a loved one                              | • Name two methods of getting help when you are sick                           |
| • Birth control                                       | • State two questions you should ask your doctor when getting a new medication |
| • Hospital or outpatient discharge papers             | • Name three ways to eliminate transmission of the flu                         |
| • Planner/calendar                                    |  |
| • Sing a song with the word “help” in the lyrics      |  |
| • Sing a song with lyrics about illness or being sick |  |

## 5:20 – 6:15 p.m. Creating emergency contact medical cards and medical summaries

Facilitators provide emergency cards and medical summaries to participants.

It is beneficial to include a physician or nurse in this session

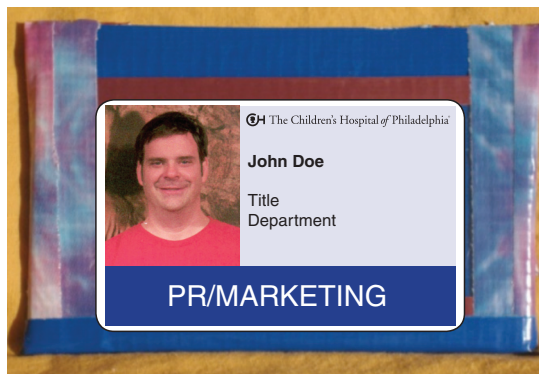
During the activity hour, participants are encouraged to work in small groups with either the physician or another medical provider to answer any questions that they may have about completing these forms in a manner that easily captures pertinent health information regarding their health status. This is an opportunity for participants to learn about organizing their medical records and other techniques to better manage illness, while advocating for themselves. It also provides a unique setting to practice these skills with medical providers directly to help increase comfort when faced with similar situations during real care encounters. If the group is highly engaged with providers and needs longer than an hour, please modify the supplemental “Duct Tape ID holder” activity shown below. Participants are encouraged to carry their cards with them at all times.

**6:15 – 7:15 p.m. Activity: Making duct tape ID holders (Example of finished project below)**

Front of ID Holder



Back of ID Holder



**Instructions for making a duct tape ID holder**

**Step 1**

Make a duct tape sheet that is 4 ½ inches long by 7 inches wide:

- Cut 16 strips of duct tape that measure 4 ½ inches each and lay the first eight pieces sticky side down on your work surface. Put the remaining eight pieces aside for now (See A on Page 28.)
- Place the second of the eight 4½-inch strips sticky side down so it slightly overlaps the edge of the first strip.
- Repeat until you have eight strips overlapping.



- Turn the sheet over so that the sticky side faces up (B).
- Take the other eight strips and do the same thing, overlapping them one on top of the other. Start at the top and work your way down. These strips get placed sticky side down. Add another strip below the last one. Remember to overlap the edges (B).
- Continue lying strips sticky side down until all of the sticky sides of the “bottom” strips are covered.
- Trim off edges.



A



B



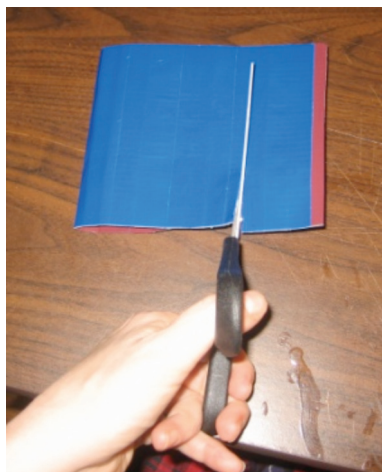
C

## Step 2

Fold the sheet in half so you have a rectangle that measures 4 ½ inches along the top (C). The short sides of the rectangle should now line up. Note: Do this before taping the other side so that the wallet will fold without bulges.

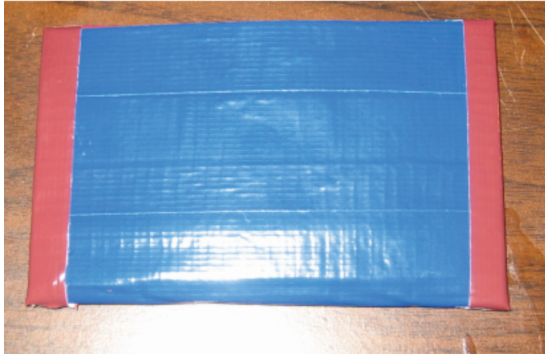
## Step 3

Measure 3 inches along the longer side and cut off the remainder of the sheet. (See picture below.)



#### Step 4

Keep the wallet in the folded position, trim any excess, and cut one strip of tape 3 inches long and rip it in half. Seal each side with one of the halves as shown below.



#### Step 5

Take the clear plastic window (already pre-cut to  $4\frac{1}{4} \times 2\frac{1}{2}$  inches) and use  $\frac{1}{3}$  of a piece of  $4\frac{1}{4}$ -inch tape to place along the top edge as shown.



### Step 6

Place the clear plastic window in the center of one side of the wallet and seal the remaining three sides down with tape.

### Step 7

Cut the remaining sheet of duct tape into two equal pieces and place them one over the other on the opposite side of the wallet.



### Step 8

Tape the sides and bottom edges down to the wallet. Your wallet/ID holder is complete. Enjoy!

**Option:** Personalize the wallet with initials, favorite colors or a personal trademark (such as musical notes if you like tunes or a logo of your favorite band or pasttime). Place your emergency medical card and photo ID in your new wallet.

### 6:15 – 7:15 p.m. Check in/Check out (concurrent with activity):

- What part of your healthcare is the most challenging and why?
- What gets in the way of taking care of your health?
- What are some difficult topics to talk about with your doctors?
- How can you teach your doctors to be better communicators?
- What types of information are the most helpful to have with you during doctor visits?
- How do you feel about using a support person to help you deal with your illness?
- Are you more comfortable in the patient or the support role? Why?
- What helps you to remember your appointments and take your medicine, or eat a nutritious diet or carry your inhaler?

### 7:15 – 7:25 p.m. Break and cleanup

### 7:25 – 7:30 p.m. Pack up and leave

**Objectives:**

- Participants will identify long- and short-term goals and learn to create SMART (specific, measurable, achievable, realistic and time sensitive) goals.
- Participants will identify obstacles to achieving these goals.
- Participants will learn to identify effective methods to overcome obstacles and increase ability to successfully meet their goals.

**Supplies:**

- journals (from Session 4)
- pens
- 25 3x5-inch index cards
- five lightweight hockey sticks
- a lightweight hockey puck
- duct tape (leftover from Session 8)

**Preparation:**

See Appendix M for setup of room. Pass out journals from Session 4.

**Schedule:**

5 – 5:15 p.m.	Dinner and icebreaker: Creating SMART dreams
5:15 – 7 p.m.	Activity: SMART Hockey
7 – 7:10 p.m.	Break
7:10 – 7:25 p.m.	Check in/Check out
7:25 – 7:30 p.m.	Pack up and leave

**Tip****Transition Tip**

Last week we created medical summaries and discussed ways to best partner with healthcare providers to help us better manage our care needs. This week we want to build on that, and think about the short- and long-term goals that are important to us and can be achieved when we are organized and thoughtful about what is needed to continue ahead. This week, try and think about the ways you can overcome any challenges that your illness may pose in your efforts to reach your goals.

**5 – 5:15 p.m. Dinner and icebreaker: Creating SMART dreams**

Facilitator(s) should hand out the journals that were given to participants in Session 4. Ask participants to write a dream list of at least three things they would like to accomplish. If the group members were able to complete their “Dream List” in Session 4, they should transform each dream into a SMART goal. The facilitators should explain the meaning of creating “SMART” goals, which should meet the following criteria:

**S** = Specific

**M** = Measurable

**A** = Achievable

**R** = Realistic

**T** = Time sensitive (long- and short-term)

For example, “My goal is to graduate from a nursing program in the next four years to attain my R.N. degree.”

5:15 – 7 p.m.

### Activity: SMART Hockey

Setup for SMART Hockey: Modify set up of the room to allow for maximum open floor space. Four group participants are chosen to play fielders. Three of these will be defenders and one will be the goalie. The remaining group participants will be the players. The facilitators should create the four positions by making “Xs” on the floor with duct tape (see diagram in Appendix M). The facilitators will referee.

The game is played with each person getting a chance to be a “player” and each person getting a chance to be a defender or goalie to try and block the player from getting the puck in the goal.

The object of the game is to get the puck past the defenders and into the goal!

#### How to Play SMART Hockey:

1. The game begins with the first player announcing his/her top goal that he/she came up with in the icebreaker activity.
2. The fielding team then has three minutes to meet to come up with a total of three realistic obstacles in an attempt to block the player from shooting into the goal.
3. Defender No. 1 then tries to counter the player’s first goal by stating the first obstacle.
4. The player then needs to come up with a good response to the identified obstacle. The facilitator(s) acts as the “referee”(s) and judges whether the player comes up with a solution that would adequately overcome the potential barrier to advance past the first defender.
5. If the answer is accepted, defender No.1 steps aside. If the answer is not accepted, defender No. 1 stays in place.
6. The player then moves on to defender No. 2. Player restates their goal and defender No. 2 must come up with an obstacle not previously mentioned to try and block advancement. The player must respond with a solution to the second barrier that demonstrates ability to overcome issue. If the answer is accepted, defender No. 2 steps aside. If the answer is unacceptable, defender No. 2 stays in place.
7. Repeat steps five and six with the player stating another goal and for defender No. 3 to try and block.
8. The player is now free to take a shot to try and get the puck into the goal. If he is able, he gets a point. The referee keeps track of all of the players’ points. The player that gets the most points wins the game!
9. The participants in the group should all rotate to the right when the next player is up. For example, the last player becomes defender No. 1, defender No. 1 becomes defender No. 2 and defender No. 2 becomes defender No. 3. defender No. 3 becomes the goalie and the goalie gets in line to become a player.

7 – 7:10 p.m.

### Break

7:10 – 7:25 p.m.

### Check in/Check out

- What were some of the biggest obstacles identified during the game?
- Were some of the solutions to the obstacles better/worse than others? Why?
- What are the biggest rewards we get from achieving our goals? (Give examples of both tangible and intangible.)
- What happens to us when we do not achieve our goals?
- What kinds of things are helpful during these times? Who supports us?
- Do you ever get so set on reaching a particular outcome that you forget to enjoy the journey?
- What positive reinforcements or rewards can we give ourselves/one another to help us stay motivated?

7:25 – 7:30 p.m.

### Pack up and leave

**Objectives:**

- Identify progress and any lessons learned and changes participants have made in their lives over the past 10 weeks.
- Participants will identify and communicate positive affirmations about each group member and share with the group.
- Participants will complete the satisfaction survey (see Appendix C) to help facilitators choose activities that best worked for the group.

**Supplies:**

- 3x5 index cards, one for each person
- “I have learned” poem created by group members in Session 4 (copies should have been made of the group composite poem)
- graduation certificates for all participants (see Appendix N)
- glamour shots (photos from Session 4) placed in frames
- REACH-OUT Satisfaction Surveys, one per person (see Appendix C)

**Preparation:**

- Hand out copies of the poem that the group created together during Session 4.
- Hand out index cards and pens, one per person.
- Give out glamour shots for participants to take home.
- Arrange graduation certificates (see Appendix N) to commemorate the work that participants did in group.
- Hand out REACH-OUT satisfaction survey (see Appendix C) group evaluations for participants to complete.

**Schedule:**

5 – 5:15 p.m.	Dinner and icebreaker
5:15 – 6 p.m.	Activity: “You Rock!”
6 – 6:45 p.m.	Evaluation and focus group
6:45 – 7:30 p.m.	Cake and celebration

**5 – 5:15 p.m. Dinner and icebreaker**

- What surprised you the most about participation in the REACH-OUT group?
- What is one thing that you will take away from group that you may not have known or realized before you joined?

**5:15 – 6 p.m. Activity: “You Rock!”**

Summary: Purpose is to celebrate the time that we have spent together and show appreciation for the struggles we have shared and the support given to one another. Each member will be given an index card. Tell participants to write their names on the front of the cards and the facilitator should then mix up the cards and hand them out. Each member of the group will write three comments or memorable traits about the person whose name is on the front of the card. The cards will be passed



around and then returned to the original person. These cards can be carried with us and will serve as reminders about who we are to one another and the contributions that we have shared.

**6 – 6:45 p.m. Evaluation and Focus Group**

The second part of our celebration will be a focus group to determine what has been most/least helpful about the group content and format. What suggestions do you have for future group activities? Do the group members have a way to get in touch with one another? The group leaders should create a sign-up sheet where members can give their name, phone number and email, if they choose to share this information.

**6:45 – 7:30 p.m. Cake and Celebration**

The facilitators of REACH-OUT have thought of many creative ways to commemorate the memorable journey the group has taken together. We have created certificates (see Appendix N), framed and given out the photos from the Session 4 glamour shots and put them on magnets, and we have typed up the poem “I have learned” created by the poetry posse in Session 4 so that they will have something special that they contributed to take away from the group.

## Appendix A: REACH-OUT Waiver and Release

This is an example of a waiver and release. Check with your organization's legal department to create a release that is appropriate.

Please check the appropriate box below indicating either that you are at least eighteen (18) years of age or older, wish to participate in the REACH-OUT Program and are signing this Waiver and Release on your own behalf, or that you are signing this Waiver and Release on behalf of your child who is younger than eighteen (18) and wishes to participate in the program.

☐ I am eighteen (18) years of age or older and I wish to participate in the REACH-OUT Program. My decision to participate in this program is voluntary.

☐ My child(ren), \_\_\_\_\_, wish(es) to participate in the REACH-OUT Program. My decision to allow my child(ren) to participate in this program is voluntary. I certify that I am the parent/legal guardian of the above-named child(ren).

I, for myself, my child(ren), our heirs and assigns, hereby waive, release and forever discharge (*name of organization*) \_\_\_\_\_ and its officers, employees, medical staff, agents, affiliated companies and subsidiaries from any and all claims, liability, loss, damages and expenses arising directly or indirectly from, or in connection with my participation in, or my child's participation in, the REACH-OUT Program. This Waiver and Release covers all aspects of the REACH-OUT Program, including but not limited to activities, research and classes at (*name of organization*) \_\_\_\_\_, trips off site as part of the program, transportation to and from those trips, and all activities on those trips.



By signing below I acknowledge that I have read this Waiver and Release, that I understand it and that I agree to its terms.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix B: Sample Video and Photo Consent Forms *(Side 1)*

This is the copyrighted Photo Release used by The Children's Hospital of Philadelphia. It is included only as an example. Check with your organization's legal department to create a release that is appropriate.

<div style="text-align: center;">  <b>The Children's Hospital of Philadelphia</b> </div> <div style="text-align: center; margin-top: 20px;">  </div> <div style="text-align: right; margin-top: 10px;"> <small>OR-102 Rev. 10/06</small> </div> <div style="text-align: center; margin-top: 20px;"> <b>CONSENT AND RELEASE FOR RECORDING OR FILMING (PAGE 1 OF 2)</b> </div>	<div style="border: 1px solid black; height: 100px; margin-top: 10px;"></div>
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I give permission for \_\_\_\_\_ to take  
**Print Name of Department/Division**

photographs, films and/or audiovisual recordings of \_\_\_\_\_  
**Print Name of Patient** **Age**

for two years from the date this form is signed.

I allow the photographs, films or audiovisual recordings ("Images") taken of the patient, to be used and released by representatives of The Children's Hospital of Philadelphia and/or its affiliates ("CHOP") for purpose(s) I have initialed below. CHOP may use and release the Images (and other information I give permission for in this form) for the purposes I authorize below until CHOP no longer has the Images.

I give permission for CHOP to use and release these Images:

\_\_\_ **For treatment, payment and internal activities of CHOP, for example:**

- Diagnosis and/or treatment of the patient by clinicians.
- Providing information to insurance companies for purposes of supporting requests for payment.
- Internal activities such as staff training and improving the quality of care.

\_\_\_ **For educational activities outside of CHOP, for example:**

- Publications in medical textbooks and journals.
- Presentations to professional and/or medical boards/societies.

\_\_\_ **For marketing and media relations activities of CHOP, for example:**

- Hospital publications and/or videos.
- Broadcast or print media, including television, radio, newspaper, magazines, and the Internet.
- Printed materials (brochures, posters, etc.).

\_\_\_ **Other** *(describe any other purpose for which the Image will be used or released, including a description of who will use the Images within CHOP and/or receive the Images outside of CHOP):*

\_\_\_\_\_

\_\_\_\_\_

**Permission to Use and Release Patient Name and Other Information with the Images:** Some Images themselves may identify the patient (for example, pictures that show a patient's face). In some cases, CHOP may wish to use or release the patient's name along with the Images. Please initial one of the following for use of the patient's name with the Image:

\_\_\_ **I agree** to the use and/or release of the patient's name with the Images.

\_\_\_ **I do not agree** to the use and/or release of the patient's name with the Images.

I also allow the following patient information to be used and/or released along with the Images:


\_\_\_\_\_

\_\_\_\_\_

AEL 5/2007

## Appendix B: Sample Video and Photo Consent Forms (Side 2)

This is the copyrighted Photo Release used by The Children's Hospital of Philadelphia. It is included only as an example. Check with your organization's legal department to create a release that is appropriate.

<div style="text-align: center;"> <b>The Children's Hospital of Philadelphia</b></div> <div style="text-align: center; margin-top: 20px;"><small>OR-102 Rev. 10/06</small></div> <div style="text-align: center; margin-top: 20px;"><b>CONSENT AND RELEASE FOR RECORDING OR FILMING (PAGE 2 OF 2)</b></div>	<div style="border: 1px solid black; height: 150px; margin-top: 10px;"></div>
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**Understanding this Authorization:**

- My decision to sign this authorization will not usually affect the patient's ability to get care at CHOP. At times, CHOP may be required to record or film the patient to provide medical services. If I do not agree to the recording or filming in these situations, services may not be provided.
- I understand that CHOP may use and release Images as the law requires or allows without further permission from the patient, even if I do not agree. See the CHOP Notice of Privacy Practices for details about how medical information, including Images, may be used and shared without further permission from the patient -- [http://www.chop.edu/about\\_chop/hipaa/npp.shtml](http://www.chop.edu/about_chop/hipaa/npp.shtml)
- After signing this form, I can change my mind and ask that recording or filming stop. If I change my mind after recording or filming is done, I can notify the CHOP Department / Division indicated above in writing to ask that the Images not be used or released. This will not change any use or release of the Images by CHOP before receiving my notice. If the Images were released outside of CHOP, I understand the Images may continue to be used even after I withdraw my permission for CHOP to use or share them.
- If I allow CHOP to release Images to other individuals or organizations, I understand that the recipients could use, distribute, broadcast and/or publish them in ways that do not protect the patient's privacy and that CHOP cannot control.
- The Images belong to CHOP. I will not be paid for the use or release of the Images.

By signing, I understand that I am authorizing CHOP to take, use and release Images of the patient as described above.

<b>Signature</b>	<b>Print Name</b>	<b>Date</b>

Relationship to Patient:   ☐ Patient   ☐ Parent   ☐ Legal Guardian   ☐ Other: \_\_\_\_\_

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**TO BE COMPLETED by CHOP STAFF**

**Brief description of Image:** \_\_\_\_\_

**Indicate type of Images taken:**   ☐ Photograph   ☐ Film   ☐ Audio Recording   ☐ Other: \_\_\_\_\_

**Print name of individual taking the Images and indicate affiliation with CHOP by checking below:** \_\_\_\_\_

☐ CHOP Employee   ☐ Contractor   ☐ News Media   ☐ Other \_\_\_\_\_

**Print name of Hospital representative supervising the recording:** \_\_\_\_\_

**Location where Images will be stored, if other than the patient's medical record:** \_\_\_\_\_

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## Appendix C: REACH-OUT Satisfaction Survey

We want to know how you rate your experience in REACH-OUT was. Answer these following questions as honestly as you can.

	Strongly Disagree	Disagree	Agree	Strongly Agree
REACH-OUT was a good use of my time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would recommend REACH OUT to other teens with a chronic illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned a lot about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned how to take care of my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned how to better cope with stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned how to communicate better with my doctors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have more confidence in myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned how solve problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can handle my disease better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had fun.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was bored a lot.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wish I never participated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not feel comfortable with the other teens in my group.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not feel comfortable with the REACH-OUT leaders.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am using the skills I learned.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall rating: Please rate your experience with:

	Poor	Satisfactory	Good	Excellent
The entire REACH-OUT program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The REACH-OUT leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*continued on next page*

*continued from previous page*

The following topics/activities were covered each session during REACH-OUT. Please rate how comfortable you felt with each task.

	Not at all	Slightly	Fairly	Completely
Discussing personal information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking/communicating with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Expressing my emotions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accepting my diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Solving problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coping with stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifying unhealthy relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with peer pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organizing my health information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking my medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Following my doctors' advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Figuring out my goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making my goals happen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. What did you enjoy most about REACH-OUT? \_\_\_\_\_

\_\_\_\_\_

2. What was the most helpful thing you learned? \_\_\_\_\_

\_\_\_\_\_

3. What can we make better? \_\_\_\_\_

\_\_\_\_\_

4. Is there anything else you want us to know about your experience in REACH-OUT? \_\_\_\_\_

\_\_\_\_\_



## Appendix D: How to Play Guesstures®

Guesstures takes charades to a completely new level. You'll be jumping up and down trying to make your team guess the right word. It's easy to learn and quick to play, so it's the perfect game whether you have a big or small group.

Instructions:

1. Divide into two teams. Teams don't have to be even, so an odd number can still play. The teams will alternate turns and send a different actor to Guesstures each time.
2. Grab four cards from the blue deck when it's your turn to Guesstures. There will be two words written on every card — pick one from each card you will act out. This gives you a total of four words to Guessture.
3. Set the Mimer-Timer on a table in front of you and open the arm. Push up the switch and wind it as far as it will go.
4. Place your four cards in the Mimer-Timer. Put them in order from easiest to hardest with the easiest on the left.
5. Start the timer by putting the arm down on the Mimer-Timer. Begin to Guesstures and get your team to shout out the word on your card.
6. Grab the card once your team shouts out the word, but be quick. If you're too slow the card will drop into the Mimer-Timer and you won't get any points for that word — even if your team guessed correctly.
7. Tally the points for the words you were able to get your team to guess. Enter that number on the side of the Mimer-Timer under Scene One.
8. Follow Steps 2 to 6 for team two.
9. Start Scene Two once everyone has Guesstured once. Choose cards from the red deck this time. Play continues as in Steps 2 to 7 for Scene Two.
10. Count all the points on the side of the Mimer-Timer after completing Scene Two. The team with the highest score wins!

*Based on instructions from Guesstures® 1999 edition*

## Appendix E: How to play Catch Phrase®

The game is played in two teams. The goal for each player is to get his or her team to say the word displayed in the disc.

1. One member of a team starts the timer and tries to get his or her team to guess the displayed word. A clue-giver can make any physical gesture and give almost any verbal clue. However, one may not say a word that rhymes with the word, give the first letter of the word, say the number of syllables, or say part of the word in the clue (e.g., "worry" for "worry wart").
2. When the team guesses correctly, the other team takes its turn.
3. Play continues until the timer runs out. The team not holding the disc when time runs out scores a point. They also have one turn to guess the word that the other team did not guess. A correct answer earns a bonus point. The first team to seven points wins.

*Based on instructions from Catch Phrase® 2007*

## Appendix F: Names of Emotions (to place on Jenga® blocks)

Exhausted	Confused	Ecstatic	Guilty	Suspicious	Lazy
Angry	Hysterical	Frustrated	Sad	Confident	Excited
Embarrassed	Energetic	Mischievous	Disgusted	Frightened	Lively
Enraged	Ashamed	Cautious	Smug	Depressed	Fulfilled
Overwhelmed	Hopeful	Lonely	Love struck	Jealous	Uncomfortable
Bored	Surprised	Anxious	Shocked	Shy	Handsome
Happy	Ambivalent	Spiritual	Content	Tired	Tolerant
Accepting	Affectionate	Curious	Interested	Questioning	Flustered
Fearful	Loved	Fierce	Awful	Sickened	Sexy

## Appendix G: How to play Jenga®

Object of the game is to remove one block at a time from the tower, and stack it on top. The last player to stack a block without making the tower fall wins the game.

*Setup:*

1. One player builds the tower on a flat, sturdy surface using the loading trap. Place three blocks in each layer, at right angles to the previous layer. When you finish, you will have a solid, 18-story tower that can more than double during play.
2. Use the loading trap to set the tower upright. Then carefully slide the tray away, and put it aside.

*To play:*

1. Pick a player to go first. Play continues to the left.
2. On your turn, carefully remove a block from anywhere BELOW the highest completed story. Then stack it on the top of the tower, at right angles to the blocks just below it.
3. Removing and Stacking Blocks
  - Remove and stack one block per turn. To remove a block, use one hand at a time. You can switch hands whenever you wish.
  - As play proceeds and the weight of the tower shifts, some blocks become looser than others and are easier to remove. You can touch other blocks to find a loose one, but if you move a block out of place, you must fix it (using one hand only) before touching another block.
  - While stacking, always complete one three block story before starting a higher one.
4. Your turn ends 10 seconds after you stack your block, or as soon as a player to your left touches a block.
5. Keep removing and stacking blocks until the tower falls. A real pro can build 36 stories high — or more!

*Instructions adapted from Jenga® 1995 edition*

## Appendix H: I Have Learned (Anonymous)

I've learned that some issues you just have to let go.

I've learned that blood is not always thicker than water.

I've learned that money can't buy you love.

I've learned that humiliation can also be your motivation.

I've learned that you have to make mistakes to learn from them.

I've learned that even when you have your heart broken, you can still love.

I've learned that you can always forgive, but you can't always forget.

I've learned that people you love try to protect you, but can't always protect you.

I've learned that the ones you love can wind up hurting you the most, and the worst!!!

I've learned that the more I learn, the more there is to know, and I will never stop learning as long as I live ...

I have learned that being a good listener does not always mean that you will be listened to.

I have learned that you will never possess that which you are unwilling to pursue.

I have learned that you need to respect yourself in order for others to respect you.

I have learned that you always have to think before you act.

I have learned that the more I live, the more I have to learn.

*Written by the Fall and Spring 2011 REACH-OUT groups*

# Appendix I: Yoga Alternative Activities

## Healthy Imagery

Guided imagery can help teens with chronic conditions or other illnesses cope with the pain and the stress they may experience.

Read more: <http://bit.ly/livestronghealthyimagery>

## Deep Breathing

Teens can use deep breathing to help relax their bodies. Deepbreathing may even assist with alleviating certain medical conditions, such as insomnia, according to research. Deep breathing exercises are easy to perform and can be done almost anywhere and at any time.

Read more: <http://bit.ly/livestrongdeepbreathing>

## Progressive Muscle Relaxation

Progressive muscle relaxation is a technique that can help teens develop awareness of their bodies while helping to quiet their minds and induce feelings of relaxation.

Read more: <http://bit.ly/livestrongmusclerelax>


## Appendix J: Instructions for “Getting to Know You REACH/BINGO”

Each participant is provided one BINGO card. The goal is for each member of the group to find another member of the group who can answer or affirm a statement on the card. When someone can answer, they are asked to initial the participant’s card. The first person to complete a row, column or diagonal line wins. The game can then continue until someone completes the entire board.


Who has traveled to another state? _____	Who plays a sport? _____	Who can snap their fingers? _____	Who knows the name of this building? _____	Who knows DeSean Jackson’s number? _____
Who has more than one sibling? _____	Who has their natural hair color? _____	Who has gone to a Phillies game? _____	Who speaks a foreign language? _____	Who can do the Eagles chant out loud? _____
Who was not born in Philadelphia? _____	Who is wearing jeans? _____	<b>FREE</b>	Who has a picture ID? _____	Who plays a musical instrument? _____
Who likes to write poetry or lyrics? _____	Who has a pet? _____	Who knows the name of Pennsylvania’s governor? _____	Who has gone to a concert? _____	Who loves pizza? _____
Who plays video games? _____	Who schedules their own doctor’s appointments? _____	Who knows the mascot for Temple? _____	Who knows the artist who sings “Respect”? _____	Who can whistle? _____

# Appendix K: Sample Emergency Contact Card


Update the form with the patient's information.



1. Fold paper in half from left to right.



2. Fold in half from top to bottom.



3. Fold in half from left to right.




FOLD 3

FOLD 1

FOLD 2

## Emergency Information

**If this is an emergency, call 911 then call** \_\_\_\_\_  
**or** \_\_\_\_\_  
**Primary Specialist's #** \_\_\_\_\_  
 If it's nearby, please have the ambulance take me to this hospital: \_\_\_\_\_  
 \_\_\_\_\_  
**Hospital's phone #:** \_\_\_\_\_  
**Has implanted medical device?**  
☐ Yes \_\_\_\_\_ ☐ No  
**Is on medication?**  
☐ Yes (Medications listed inside.) ☐ No  
**Has allergies?**  
☐ Yes (Allergies listed inside.) ☐ No  
**Has a complex medical condition?**  
☐ Yes (See additional info inside.) ☐ No

**Additional contact information:** \_\_\_\_\_  
 \_\_\_\_\_  
**Treatment during most recent hospitalization:** \_\_\_\_\_  
 \_\_\_\_\_  
**Date and reason for most recent hospitalization:** \_\_\_\_\_  
 \_\_\_\_\_  
**Allergies (include allergy and reaction):** \_\_\_\_\_  
 \_\_\_\_\_  
**Medications (include dose & time taken):** \_\_\_\_\_  
 \_\_\_\_\_  
**Diagnosis & history:** \_\_\_\_\_  
 \_\_\_\_\_  
**Religion:** \_\_\_\_\_  
**Med. Insurance Co.:** \_\_\_\_\_ **Policy #:** \_\_\_\_\_  
 \_\_\_\_\_  
**Address:** \_\_\_\_\_  
**Date of birth:** \_\_\_\_\_ **Sex:** ☐ M ☐ F  
**Name:** \_\_\_\_\_

FOLD 2

FOLD 1

FOLD 2



CUT ALONG DASHED LINE. CHOP reviewed 4/10

Used with permission from Symme Trachtenberg, M.S.W., CHOP



# Appendix L: Medical Summary Form – Insert

## LEGAL NAME

Address, City, State, Zip  
Phone, cell, email

INSURANCE	Company Name	Certificate # ADD	BC Plan ADD / BS Plan ADD	Rx BIN ADD
		Group # ADD	ADD PH / 800-XXX-XXXX	

Legal Health POA *	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD
	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD
	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD

DOB xx-xx-19xx

HEIGHT/WEIGHT: x'x", xxx lbs

ADVANCE DIRECTIVES: YES NO

DNR: YES NO

SS# xxx-xx-xxxx

BLOOD TYPE: X positive/negative

ORGAN DONOR: YES NO

- ADD comment about pain threshold
- ADD comment regarding patient preference
- ADD comment regarding patient preference.

## ALLERGY: ADD

HEALTH ISSUES			
ADD Body system	ICD-9 XXX	ADD Name of Health Issue	age on onset
ADD Body system	ICD-9 XXX	ADD Name of Health Issue	age on onset

MEDICATIONS					
Rx	What for?	Name of Drug Dosage x ? how many times a day, ADD RX #			
OTC		List any over the counter Drug –indicate daily or PRN			
MEDICAL HISTORY					
Add Body System	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age next episode
	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age on onset
	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age on onset
	SURGERIES				
	ICD9 - XXX	What treatment? Note if benign or cancer	age on onset	age next episode	age on onset
	ICD9 - XXX	What treatment? Note if benign or cancer	age on onset		
Add Body System	ICD9 - XXX	Diagnosis?	age on onset	age next episode	
OTHER		Diagnosis?	age on onset	age next episode	
			age on onset	age next episode	

MEDICAL TESTS			
Blood	Month/Year	Fasting	Cholesterol XXX, HDL XX, LDL XX, Trig XXX, CRP XX, glucose XX
	Month/Year	Negative	- Name of Company, Address
	Month/Year	Normal	- Name of Company, Address

IMMUNIZATIONS					
Tetanus	YR	TB	YR	Pneumococcal vaccine	YR

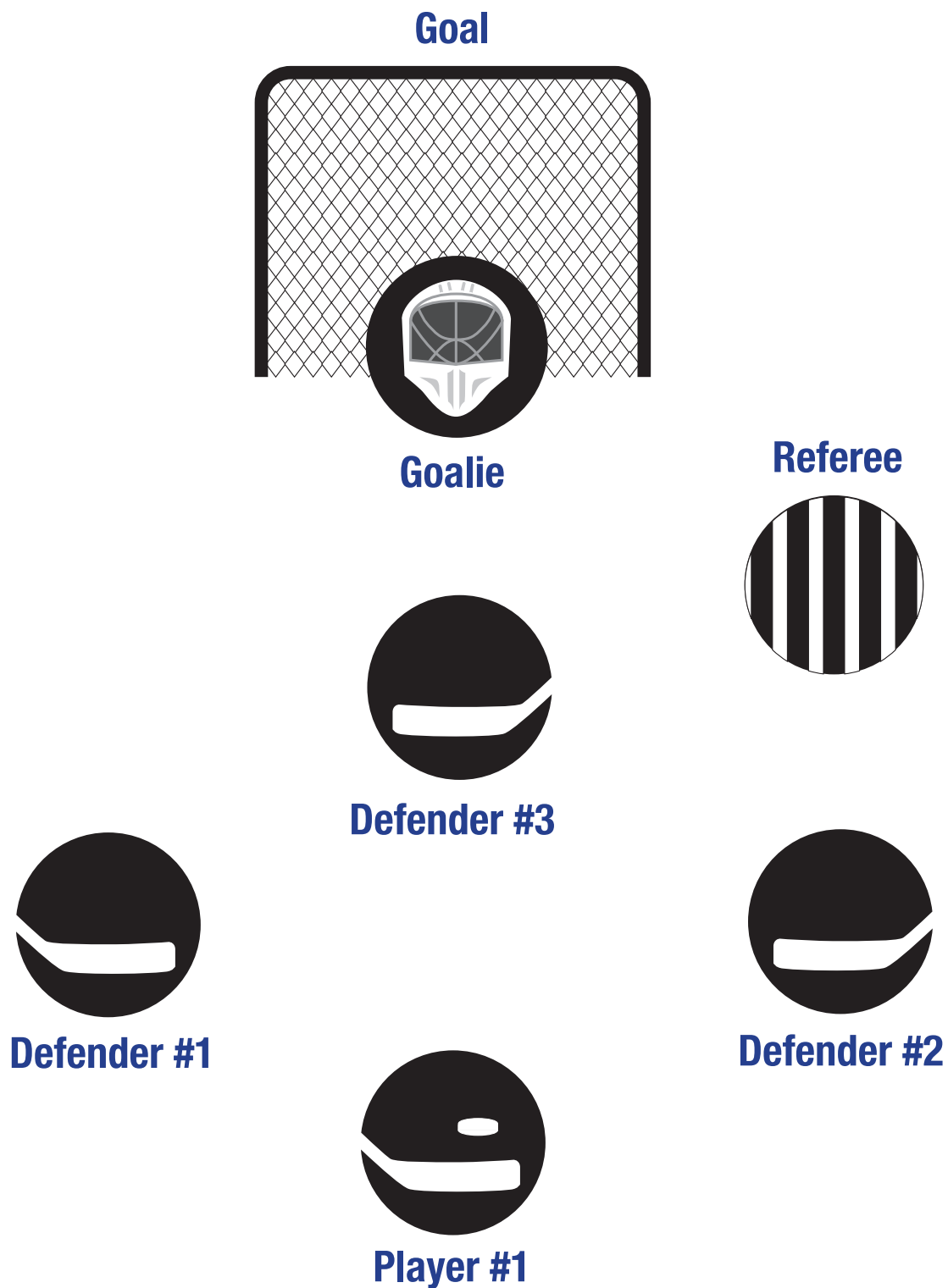
FAMILY HISTORY		
Father	Alive/Deceased Age?	Health Issues, Cause of Death
Mother	Alive/Deceased Age?	Health Issues, Cause of Death
Child	Alive/Deceased Age?	Health Issues, Cause of Death

PHYSICIANS			
FAMILY PRACTICE	Name	Phone	Address
	Name	Phone	Address

OTHER			
Dental	Name	Phone	Address
Rx -Pharmacy	Name	Phone	Address

Form courtesy of the HRTW National Resource Center. For online versions of this Portable Medical Summary form and others, go to: [http://web.syntiro.org/hrtw/tools/check\\_care.html](http://web.syntiro.org/hrtw/tools/check_care.html).

## Appendix M: Setup for Session 9 Activity: SMART Hockey



*Remaining players line up behind Player #1*

## Appendix N: Sample Participant Graduation Certificate

An illustration of six diverse children of various ethnicities and ages. They are holding large letters that spell out 'REACH OUT!'. The letters are: 'R' (white), 'E' (yellow), 'A' (orange), 'C' (white), 'H' (black), and 'O U T!' (white with colorful dots). The children are standing on a blue background.

*congratulations*

This will certify that \_\_\_\_\_ has completed the  
Reach Out program at the Children's Hospital of Philadelphia  
from \_\_\_\_\_ through \_\_\_\_\_  
*Date of First Session* *Date of Last Session*

*Thank you* for your amazing contribution to our program for teens  
and young adults living with chronic illness. We have enjoyed spending this  
memorable time with you! *Congratulations!*

\_\_\_\_\_  
*Facilitator*

\_\_\_\_\_  
*Facilitator*

The logo for The Children's Hospital of Philadelphia, featuring a stylized 'CH' in a circle.

The Children's Hospital of Philadelphia®

Hope lives here.

## Appendix O: List of Materials Needed for REACH-OUT

- 200 lined colored 3 × 5-inch index cards
- two small empty cardboard boxes for game cards
- one pad of 22 × 28-inch poster paper
- easel
- prizes: can be nominal items, \$5 gift cards, water bottles, stuffed animals, nail polish, movie tickets, mugs, etc. Approximately 20
- Guesstures® game
- Catch Phrase® game (electronic version)
- three AAA batteries
- 54 white 1 × 2<sup>5</sup>/<sub>8</sub>-inch labels (two sheets)
- Jenga® game
- balloon air pump (not helium)
- permanent markers (12)
- one pack dry-erase markers
- 3 small packs of balloons – (15) red, (30) yellow and (15) blue
- crayons, markers, colored pencils and pens
- tape or glue
- yoga DVD
- DVD player
- journals — plain covers suitable for decorating — one per person
- decorations for journals — stickers/felt lettering/magazine cutouts, etc.
- camera for photos
- makeup, nail polish and clean applicators
- copies of “I Have Learned” poem – one per person (see Appendix H)
- one pad of blank 8 × 11-inch paper
- one 13.30-ounce bag of either M&M’s or Starburst (or sugar-free colorful candy, if needed)
- 30 4 × 5-inch labels/name tags that can be taped or with adhesive on the back to attach to clothing
- copies of “Getting to Know You REACH/BINGO” card (see Appendix J).  
One per group member.
- large dry-erase board and erasable markers or chalkboard and chalk
- two buzzers or two bike horns
- timer (three minutes) or stopwatch
- colorful rolls of duct tape
- three 8 × 10-inch sheets of clear plastic cut into 4<sup>1</sup>/<sub>4</sub> × 2<sup>1</sup>/<sub>2</sub>-inch pieces  
(One piece per person.)
- emergency contact cards (see Appendix K), one per person
- medical summary forms (see Appendix L), one per person
- crafting knife or sharp scissors (two or three for group to share)
- rulers (two or three for group to share)
- 5 lightweight hockey sticks
- one lightweight puck
- “I Have Learned” poem created by group members in Session 4  
(copies should have been made of the group composite poem)
- graduation certificates for all participants (see Appendix N)
- group evaluations (see Appendix C)
- glamour shots (photos from Session 4) placed in frames

# References

- Chesney MA, Chambers DB, Taylor JM, Johnson LM, Folkman S. **Coping effectiveness training for men living with HIV: Results from a randomized clinical trial testing a group-based intervention.** *Psychosom Med.* 2003;65(6):1038–1046.
- DiNapoli PP, Murphy D. **The marginalization of chronically ill adolescents.** *Nurs Clin North Am.* 2002;37(3):565–72.
- Erikson EH. **Identity: Youth and Crisis.** New York, NY: Norton; 1968.
- Lazarus RS, Folkman S. **Stress, Appraisal and Coping.** New York, NY: Springer Publishing Co.; 1984.
- LeBlanc LA, Goldsmith T, Patel DR. **Behavioral aspects of chronic illness in children and adolescents.** *Pediatr Clin North Am.* 2003;50(4):859–878.
- Merlijn VP, Hunfeld JA, van der Wouden JC, Hazebroek-Kampschreur AA, Koes BW, Passchier J. **Psychosocial factors associated with chronic pain in adolescents.** *Pain.* 2003;101(1-2):33–43.
- Miauton L, Narring F, Michaud PA. **Chronic illness, lifestyle and emotional health in adolescence: Results of a cross-sectional survey of the health of 15 to 20 year olds in Switzerland.** *Eur J Pediatr.* 2003;162(10):682–9.
- Newacheck PW. **Poverty and childhood chronic illness.** *Arch Pediatr Adolesc Med.* 1994;148(11):1143–9.
- O'Dougherty M, Brown TR, eds. **The Stress of Childhood Illness in L. Eugene Arnold.** *Childhood Stress.* Canada: John Wiley and Sons; 1990:325–347.
- Pacaud D, Crawford S, Stephure DK, et al. **Effect of type 1 diabetes on psychosocial maturation in young adults.** *J Adolesc Health.* 2007;40(1):29–35.
- Plante WA, Lobato D, Engel R. **Review of group interventions for pediatric chronic conditions.** *J Pediatr Psychol.* 2001;26(7): 435–53.
- Pless IB, Power C, Peckham CS. **Long-term psychosocial sequelae of chronic physical disorders of childhood.** *Pediatrics.* 1993;91(6):1131–6.
- Schopler JH, Galinsky MJ. **Support groups as open systems: A model for practice and research.** *Health Soc Work.* 1993;18(3):195–207.
- Seiffge-Krenk. **Chronic disease and perceived developmental progression in adolescence.** *Dev Psychol.* 1998;34(5):1073–84.
- Stam H, Hartman EE, Duerloo JA, Groothoff J, Grootenhuis MA. **Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood.** *J Adolesc Health.* 2006;39(1):4–13.
- Stark LJ, Bowen AM, Tyc VL, Evans S, Passero MA. **A behavioral approach to increasing calorie consumption in children with cystic fibrosis.** *J of Pediatr Psychol.* 1990;15(3):309–326.
- Stevens SE, Steele CA, Jutai JW, Kalnins IV, Bortolussi JA, Biggar WD. **Adolescents with physical disabilities: Some psychosocial aspects of health.** *J Adolesc Health.* 1996;19(2):157–64.
- Suris JC, Parera N, Puig C. **Chronic illness and emotional distress in adolescence.** *J Adolescent Health.* 1996;19:153–56.
- Suris JC, Michaud PA, Viner R. **The adolescent with a chronic condition. Part 1: Developmental Issues.** *Arch Dis Child.* 2004;89(10):938–42.
- Westbom L. **Well being of children with chronic illness: A population-based study in a Swedish primary care district.** *Acta Paediatr.* 1992;81(8):625–9.
- Wolman C, Resnick MD, Harris LJ, Blum RW. **Emotional well-being among adolescents with and without chronic conditions.** *J Adolesc Health.* 1994;15(3):199–204.
- Woodgate RL. **Adolescents' perspective of chronic illness: "It's hard."** *J Pediatric Nurs.* 1998;13(4):210–223.