

Brainy Camps Association

Subsidiary of Children's National

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Objectives

1. Increase awareness of camps
2. Discuss how the camp experience produces positive behavioral changes
3. Review how interacting with children in a natural setting can impact the physicians' perceptions and treatment plans.
4. Identify opportunities for CNMC community to participate



Brainy Camps Physician Champions

Roger J. Packer, MD, Senior Vice President, Children's National, President, Board of Directors, Brainy Camps

Dorothy Bulas, MD, Chair, Professional Advisory Board

Camp Medical Directors

Steven Weinstein, MD: Great Rock: Epilepsy

Bennett Lavenstein, MD: Asperger's & Tourette syndrome

Maria Acosta, MD: New Friends: NF

Charlie Berul, MD: Heartbeat: Pacemakers, ICDs, CHD

Fran Cogen, MD: Take Charge: Diabetes

Sally Evans, MD: Take Hold: Cerebral Palsy

Amy Kao, MD: Super Smile: Down syndrome

Emily Meiers, MD: Super Campers Always: Sickle Cell Anemia

Jimmy Beck, MD: Medical Students



Development of Camps

1994 EFNCA- Establish Camp Great Rock (23 campers and 10 volunteers)

1997 Camp Great Rock joins with CNMC

2004 Camp New Friends: NF Camp

2005 Camp Connect: Tourette syndrome

Super Campers Always: Sickle Cell Anemia

2006 Transitional Youth (NF and GR)

2008 Asperger's syndrome

2009 Brainy Camps Association

2010 Pacemakers, ICDs and Diabetes

2011 Down Syndrome, Cerebral Palsy, Childhood Obesity
Congenital Heart

2012 300 campers, 150 volunteers,
Elective for residents, 13 medical students



Children with Chronic Health Conditions

- Social isolation and peer withdrawal
- Anxiety and depression
- Low self-esteem
- Learning disabilities and academic underachievement
- Increased dependency
- Increased bullying



Camp Goals: Increase

1. Knowledge
2. Adaptive coping skills and independence
3. Self Management
4. Resiliency: Hope and QOL
5. Sense of Belonging and community
6. Respite for families



Camp Design

Traditional Residential Camp

Camper to Counselor Ratio: 2 to 1

Educational seminars

Support groups (3-4/wk)

24 hour Medical Staff

Counselors in Training (CITs)

Upward mobility of campers

Counselors & CITs with condition, mentors

*Collaboration with hospital divisions and departments (6)

Partnerships with national and local health organizations



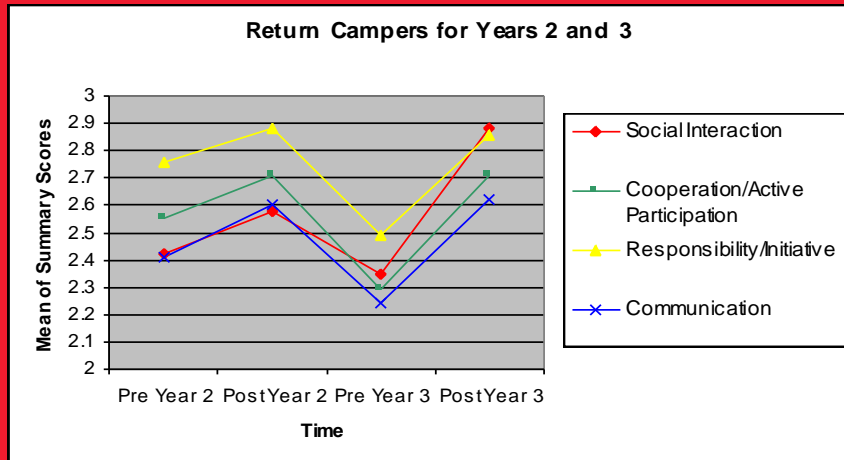
Mean change: domain summary scores CABS pre and post camp/ year

	Year 1 (1998) (n=34)		Year 2 (1999) (n=39)		Year 3 (2000) (n=56)	
	Change	p-value	Change	p-value	Change	p-value
Social Interaction	.31	.01**	.27	.04*	.548	<.01**
Cooperation/Active Participation	.15	.16	.26	.08	.513	<.01**
Responsibility/Initiative	.04	.91	.11	.31	.437	<.01**
Communication	.35	.01**	.11	.26	.411	<.01**

* p<.05, ** p<.01



Mean summary scores for campers attending all 3 years (n=28)



Benefits: Condition Specific Camps

***A specialty camp for children can improve adaptive behaviors and social interaction**

Improvement in social interaction is a significant and consistent finding over the three year study

Gains - largely sustained from year to year

Continued camp participation leads to additional benefits for return campers

***Booster sessions, maintain connections**



Benefits for the Medical Team

1. Management of care: clinic to the community
Observe and interact with children in a natural environment. Understand the impact of care.
2. Improve advocacy and education for families
3. Improve doctor-patient relationship & compliancy
4. Train medical students & residents
5. Present research opportunities

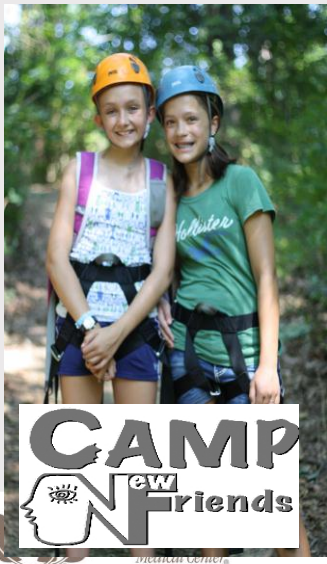


Questions for the Medical Team

1. How do children with chronic conditions benefit from a camp experience? *Roger Packer MD, Joanna Rosenthal, MD*
2. How can trainees benefit from participating in a camp experience? *Fran Cogen, MD, Bennett Lavenstein, MD*
3. How has participating in the camps changed your approach to patient care? *Steven Weinstein, MD*



Roger Packer, MD, Director, Gilbert Family Neurofibromatosis Institute



**Roger Packer, MD and Ken Rosebaum, MD
Teaching Campers**



**NF Clinic Coordinator : Genetic Counselor Deborah
Nurses: Peter, Shanon, Susan**



"Nobody feels left out"



Camp New Friends: "Camp is a place where everyone knows your name and the worries are all the same."



**Charlie Berul, MD, Chairman Cardiology
Joanna Rosenthal, MD**



**Camp Heartbeat: Nurses and Exercise Physiologist
Megan, Carol, Beth, Meghan, and Vicki**



"I met other kids like me"



At Camp Heartbeat: "I danced my heart out!"



"I feel so alive"



Fran Cogen, MD
Director, Diabetes Program



Camp Take Charge Medical Team

Michelle, Fran, Celia, Justine



"Everyone cheers you on. It's empowering"



I got to try new activities



Camp Take Charge Trainee Learning Objectives

1. To *observe* adolescents with diabetes in the real world (outside hospital/or clinic) (psycho-social related concerns)
2. To *perform* diabetes related management skills on a daily basis
3. To *synthesize* blood glucose monitoring, carbohydrate counting with appropriate insulin dosing and administration (clinical decision making)



How can trainees benefit from participating in a camp experience?

1. Inserting theory into practice
2. Living among children with chronic illness (diabetes) 24/7: 4 days/ 3 nights
3. Observation of adolescents with chronic illness (diabetes) with each other- *normalization*
4. Apply decision making and practical skills:
 - Blood glucose monitoring
 - Insulin injections
 - Psychosocial issues
 - Nutrition and Exercise



Bennett Lavenstein, MD
Nurses: Audrey, Leslie, Stephanie



Camp Connect: “Camp has been an oasis, a spring of insight rejuvenation for both my son and for us as parents.”



Camp Connect



Camp Connect



Camp Great Rock

Steven Weinstein, MD, Medical Director: 18 yrs





Chief Justice John Roberts
US Supreme Courts

Campers Live with Epilepsy and Stigma

- 29% uncomfortable telling friends/family about their condition.
 - 20% not comfortable answering questions about their epilepsy.
 - 48% felt friends or family attitudes towards them changed after revealed their epilepsy.
 - 56% employed not comfortable telling employer or colleagues that they have epilepsy.
 - 52% respondents experienced stigma as result of their epilepsy.
 - 48% use of the label **"an epileptic" to be offensive.**
- Of these 57% experienced stigma as a result of epilepsy.

*Epilepsy & Stigma Survey
Brainwave – The Irish Epilepsy Association
February 2012



"My son blossomed from an angry sad boy to a self assured young man in the making. I contribute these changes to camp"



**"My son learned that his disorder does not
have to stop him from doing whatever he desires"**



Camp Super Smile





Camp Take Hold



Super Campers Always



"Camp helped us grow as a family"

