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Research on Children and Families Affected by CHD

Following are some published studies that document the needs addressed by Camp del Corazon. We have found that this is an extremely underserved and deserving group of children and families and we appreciate your support in our mission!

Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review

Beatrice Latal¹, Susanne Helfricht¹, Joachim E Fischer², Urs Bauersfeld³ and Markus A Landolt^{4*}

This review demonstrated that a significant proportion of children with CHD experience psychological maladjustment following cardiopulmonary bypass surgery. Children with more severe heart defects, or those in need of future surgical interventions and children with neurodevelopmental impairment are at particular risk for maladjustment. The QoL of these children appears also to be affected, particular with regard to parental reports. However, the literature on this important outcome is still emerging and disease-specific instruments have just been published. Importantly, parental well-being seems to be related to psychological adjustment in these children. This calls for an integrated approach to family support, taking the child's individual needs into account as well as the needs of the parents.

<http://www.biomedcentral.com/1471-2431/9/6>

Emotional and Behavioural Problems in Children and Adolescents with Congenital Heart Disease

Beena Johnson¹ & Johnson Francis²

There is high prevalence of behavioural and emotional problems in children and adolescents with congenital heart disease. Early detection of distressed families will help in alleviating stress and reducing behavior problems in children with congenital heart disease. A comprehensive approach in this field is essential, so that effective psychological interventions and guidance can be planned.

<http://files.eric.ed.gov/fulltext/EJ847489.pdf>

Covert fears, anxiety and depression in congenital heart disease.

Gupta S¹, Giuffre RM, Crawford S, Waters J.

RESULTS: Children with congenital heart diseases demonstrated more medical fears, and more physiological anxiety, than the normative samples. More specifically, children with cyanotic forms of congenital heart disease demonstrated more fears of the unknown, physiological anxiety, depression, and delinquent behaviors than the acyanotic children with congenital heart disease. Mothers of the children with cyanotic forms of congenital heart disease scored higher on both the state and trait scales, with higher maternal anxiety correlating with higher anxiety, medical fears and behavioral problems in the child.

CONCLUSION: In a clinical setting, children with congenital heart diseases who do not present with psychological adjustment problems are still at risk for covert physiological anxiety, medical fears, depression and behavioral problems. The children with cyanotic malformations represent a subgroup at higher risk for these problems, which may be further exacerbated by increased maternal anxiety.

<http://www.ncbi.nlm.nih.gov/pubmed/9855104>

Behavior and self-perception in children with a surgically corrected congenital heart disease.

Miatton M¹, De Wolf D, François K, Thierry E, Vingerhoets G.

RESULTS: Compared to parents of healthy children, those of CHD children report significantly lower school results ($p < .01$), more school problems in general ($p < .01$), and a higher percentage of their children repeated a school year ($p < .01$). They also reported more social ($p < .01$) and attention problems ($p < .01$) and more aggressive behavior ($p < .05$). On self-perception and state anxiety questionnaires, no significant differences were found between the patient group and the healthy group. On a depression scale, however, children with a surgically corrected CHD reported more depressive feelings than healthy controls ($p < .01$).

CONCLUSION: Parents of children with CHD rate their child's school competence to be weaker than healthy peers, they report more attention and social problems and more aggressive behavior. Children themselves did not report differences on perceived competence or anxiety but they do indicate more depressive symptoms than healthy peers.

<http://www.ncbi.nlm.nih.gov/pubmed/17700081>

Now that we know some of the unique struggles that children and families affected by CHD face, how does Camp del Corazon address these needs?

"The building blocks of self-esteem are belonging, learning, and contributing. Camps offer unique opportunities for children to succeed in these three vital areas and even beyond home and school."
Michael Popkin, Ph.D., family therapist and founder of Active Parenting

"The biggest plus of camp is that camps help young people discover and explore their talents, interests, and values. Most schools don't satisfy all these needs. Kids who have had these kinds of (camp) experiences end up being healthier and have less problems which concern us all."

Peter Scales, Ph.D., noted author/educator, and Senior Fellow, The Search Institute

Evaluation: To make sure we are addressing the needs of our campers, immediately following each camp session we send all volunteer counselors and camper families an extensive evaluation questionnaire. Of the children with congenital heart disease that attend our summer camp, we confirm that more than 80% receive one or more of the following: they want to come back next year; they learned one new fun skill they want to use again on their own; they made at least one new friend; and as a result of camp, they have the confidence to try at least one new thing in another setting during the school year.

Here are some additional evaluation results from our campers and parents:

Do you feel that attending Camp del Corazon has increased your child's feelings of self-esteem and self-worth? Yes: 100%

Do you feel that Camp del Corazon has allowed your child to experience independence in a safe environment? Yes: 100%

Please give us your honest opinion regarding the following questions?

- How much did your child enjoy camp? Liked or Loved: 98%
- How much did your child like his/her counselors? Liked or Loved: 97%
- Do you feel your child made new friends? Liked or Loved: 93%

Relevant Published Articles about the merits of Camp

How 'Bubble-Wrapped' Kids Benefit From Camp

<http://www.ourkids.net/blog/how-bubble-wrapped-kids-benefit-from-camp/>

The Meaning of Summer Camp

<http://content.time.com/time/magazine/article/0,9171,1820133,00.html>

Summer Residential Camps: Promoting Social Interaction and Self-Efficacy Among Young Adults With Special Needs

...many, although not all, individuals with special needs lack appropriate social skills and competencies (Burt et al. 2008). These individuals may enter an ongoing downward spiral since the deficits create a sense of failure and prevent individuals from developing motivation or initiative, resulting in low skill levels and poor self-efficacy. There is a need to develop and exercise these life skills to encourage independent living, social engagement, and community involvement. Camp can serve as a primary teaching environment to foster skills, optimism, friendships, and competence (Fine 2005; Thurber et al. 2007). To avoid marginalization and successfully overcome adversity, individuals with special needs require inclusion, support, and coaching on appropriate skills. Camps provide an inclusive environment with novel attention so individuals may experience normal aspects of development and success which will improve their spirits, confidence, and outlook toward life (Klassen and Lynch 2007). The staff-camper mode of interaction emphasizes normalcy and replaces the traditional mindset that individuals with special needs are helpless and incapable (Shaver and Scheibe 1967).

<http://www.acacamps.org/content/summer-residential-camps-promoting-social-interaction-and-self-efficacy-among-young-adults-s>

Best gift for kids? Send them to summer camp

http://www.pennlive.com/editorials/index.ssf/2011/11/best_gift_for_kids_send_them_t.html

"I have no idea what happens at camp but my daughter came back a different person. Yesterday her teacher told us Sophia was supposed to write about a "bad" day in her life. Sophia said she hasn't had one. Her teacher was surprised and mentioned her heart surgeries and heart disease and Sophia told her those aren't bad days or bad memories, she simply cannot think of a bad day in her life. Her teacher says Sophia is her hero; she's never met anyone like her. I told her she's mine too. Thank you Camp del Corazon!!!" – Camper Mom 2015

