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## EMERGING YOUTH LEADERS IN THE NEWS

*The Family Voices Network is made up of dynamic, informed, articulate parent leaders who have advocated over time for changes to the health care systems their families must access for care for their children and youth with special health care needs. It is no surprise that many of the children of these parent leaders are themselves "trailblazers" and well on their way to becoming self advocates. Two young adults who have been featured in local newspaper articles recently are Lizzy MacDonald (DE) and Zach Feist (ND). Read on to learn more.*

### "Each Day Brings Challenges: For People with Dwarfism, Simple Tasks Not Always Simple" by Kelly Bothum, The News Journal, October 2, 2007:



**Lizzy MacDonald and Mom, Beth**

Caesar Rodney students were used to seeing Lizzy MacDonald weave through the hallways at school in her motorized chair.

This day would be different.

For her high school graduation, Lizzy -- who has a form of dwarfism and stands just 2 1/2 feet tall -- wanted to accept her diploma like every other graduate. That meant no wheelchair with the fat tires and Washington Redskins mascot on the back rolling across the commencement stage. Just her metal crutches and her white dress shoes -- a toddler's size 8 1/2 -- holding her steady.

It didn't matter that her classmates towered above her. She couldn't control that. But her determination -- that she held firmly in her grasp.

"I know I'm short. It surprises people when they see me. But really, they have to get over it," said Lizzy, who is 18 and lives in Dover. "I'm just like them, but little. I can do what they do, just maybe in a different way."

For little people like Lizzy, it can be a daunting task to navigate a world in which you don't fit. Nearly everything from car pedals and fast-food counters to ATM machines and shopping carts is designed with the average-height person in mind. Door locks are too high. Clothes don't fit without extensive alterations.

Growing up small means a stuffed bookbag can feel like toting around cannonballs. Writing is a chore when your fingers go numb holding a pen for too long.

It doesn't get any easier as adults. Even then, little people make constant accommodations, whether it's bringing a stool to reach the filing cabinet at work or using a metal claw extender to reach the top shelf at the grocery store. Taken individually, these challenges may not seem like much. But as a whole, they illustrate the struggle for little people when one size doesn't fit all.

Read the entire article here: <http://www.delawareonline.com:80/apps/pbcs.dll/article?Date=20071002&Category=NEWS&ArtNo=710020338&SectionCat=&Template=printart>

## Voices From Home 2006



### NOW AVAILABLE - Voices From Home 2006 !!!

This 65-page report provides information on activities of the Family Voices network of family and youth leaders in the states. Also included are highlights from the FV project, Kids As Self Advocates (KASA), data summaries, and charts of FV state initiatives and partners. Visit the FV website to download or order through Catalog.

## Family Voices Topical Call Center



Family Voices invites Friday's Child readers to check out a new feature on our website home page—the Topical Call Center. The Topical Call Center is home to information on upcoming topical calls offered by the National Center for Family Professional Partnerships as well as information from past calls. For the latest information, please visit the Family Voices website.

## Family Matters: Parent / School Partnerships



This latest issue provides information on opportunities to support children's education and health, including School Wellness Policies & Councils and the importance of your participation at your child's school. Available at <http://www.brightfuturesforfamilies.org>

## EMERGING YOUTH LEADERS IN THE NEWS, *continued*



**Zach Feist**

### “Rebels’ Feist Overcomes Obstacles,”

by KALEN OST, The Jamestown Sun, October 09, 2007:

Every step, every play, every hit is a statement: I can do this just as well as anyone.

For Zach Feist, with every snap of the ball and with every game finished, he’s finding that statement to be more and more true. But before finding that outlet, the junior at Edgeley High School admits he was kind of a sad story. Living with only about 15 percent of his hearing, a condition he’s had since birth, there were obstacles.

“People couldn’t really understand me, I always had to go to speech,” said the junior fullback and linebacker for the Edgeley-Kulm Rebels. “When I was younger, I was a sad little kid, you

could say. I just wanted something to do. I never really got the opportunities. But one day I watched football and I’ve loved it ever since. When I was old enough to play at recess, I played it and fell in love with it there.”

But to play the game he loved required ways around his hearing difficulties. Offensively, players cannot move towards the line of scrimmage until the ball is snapped. The ball is snapped from the command of the quarterback, something Feist couldn’t always hear. So he had to find ways around what restricted him.

And while he couldn’t hear the quarterback’s cadence, his eyes work just fine.

“As a fullback, I get to see the offensive line move,” Feist said. “I’m right behind the quarterback and can see him snap the ball.”

Once a play begins, it is the end result Feist looks for. The moment when plastic is put on plastic and one side or the other will win out. In those brief seconds that encompass a play in football, being able to hear or not being able to hear is meaningless. “The noise out there is the best noise in the world,” said Feist. “I can’t hear the crowd but I can just hear the hitting of the pads, the grunting, swearing. I mean it, being out there, man, that makes me feel normal.”

“I want to approach it as one of those guys that gives it all he’s got. One of those guys recognized as the hardest hitters. I work really hard in practice and in the weight room to be a hard hitter. Sometimes I get mad at my teammates if they don’t hit me hard enough.”

Read the entire archived article here: <http://www.jamestownsun.com/articles/index.cfm?id=55316&section=sports>



## Network News

♥ Family Voices expresses condolences to **Rick Skagen, Network Member in WY**, in the passing of his father.

To subscribe to the e-newsletter version of Friday's Child, please send an e-mail to [fridayschildnews-subscribe@yahoo.com](mailto:fridayschildnews-subscribe@yahoo.com). We invite you to share announcements of news, resources, upcoming events, and other information related to children with special health care needs. Please email us at [kidshealth@familyvoices.org](mailto:kidshealth@familyvoices.org) with the subject "Friday's Child", and we will try to include your listing in our next issue. This issue of Friday's Child and archived issues are available on the Family Voices website, <http://www.familyvoices.org/pub/fc/index.php>. Please forward this website to those you would like to share Friday's Child with, or they can subscribe to [fridayschildnews-subscribe@yahoo.com](mailto:fridayschildnews-subscribe@yahoo.com).  
**Karen Anzola, Editor and Peggy Curran, Layout**

## NEWS FROM OUR PARTNERS



**Bonnie Strickland, Ph.D.** has been named the new Director of the Division of Services for Children with Special Health Care Needs (DSCSHCN) of the **Maternal and Child Health Bureau**, Department of Health and Human Services. Bonnie, the Acting Director of the DSCSHCN since the retirement of Dr. Merle McPherson, has been a champion of the importance of family professional partnerships in improving health care services for children throughout her career. Congratulations, Bonnie!!!



The **Champions for Inclusive Communities** "Connecting Communities" discussion forum is open for your participation. The introductory topic for the next two weeks (October 22 - November 5) will be "Organizing Services for Families." The goal for this topic is to allow everyone who participates in the forum to discuss ways you and your community are helping families get the services they need, as well as any innovations or processes that are particularly family friendly making the services and supports easier to use. Every community experiences successes and challenges, and this discussion is the perfect place to contribute your ideas and possible solutions to others that may be dealing with a similar issue.

ChampionsInC invites you to subscribe today to participate! We also ask you to spread the word to your network of families, communities, and organizations by forwarding this information to them.

To view and/or learn more about the discussion forum, visit the ChampionsInC website -

<http://www.championsinc.org/main/discussion.cfm>

## Network News, *continued*

♥ Family Voices welcomes **Bev Baker-Ajene as the new Project Associate** on the IMPACT project, reporting to Betsy Anderson. Bev brings a variety of experiences & skills to Family Voices, including website design and grants administration. She will complete her BS in Graphic Design, specializing in website design, in December 2008. Bev is a single parent of a six year old daughter, Yami, who was born with Cerebral Palsy. Bev has participated in Family TIES programs, focus groups, and parent-to-parent opportunities over the past two years.

Bev will work in the Boston office and can be reached at [bbajene@familyvoices.org](mailto:bbajene@familyvoices.org) or (617) 399-8323.

♥ We congratulate **Nora Wells as a recipient of the MCHB's Director's Award** presented by Peter C. van Dyck, M.D., M.P.H., Associate Administrator MCHB, HRSA, at the recent MCHB Partnership Meeting in Washington, DC. Nora has been a passionate, articulate advocate for families of CYSHCN since the birth of her son, over 30 years ago, and is currently the Director of the National Center for Family / Professional Partnerships (NCFPP) at Family Voices. In her career, she has published numerous professional articles and family-friendly resources, served as an advisor to the development of the National Survey of CSHCN, been instrumental in the design and use of data measures for Family-to-Family Health Information Centers, and served as a mentor to many, many family leaders.



**Nora Wells**

As noted by Dr. van Dyck "Nora is what we could call a leader across the life-span who helps families, children, youth and now adults with her diligence to equality, her commitment to quality, and her honesty."

**Way to Go, Nora!**



♥ **Share Your Voice !!! - A New KASA Survey & White Paper**

KASA wants to hear from youth with disabilities (ages 12-25) about their experiences with paraprofessionals (paras). If you are a youth and want to share your ideas/opinions in order to help improve they way paras work with youth, then please complete this survey, available at <http://www.fvkasa.org/resources/files/Paraprofessional%20Survey%20for%20youth%2007.doc>.

.KASA will be compiling the results of this survey in their second White Paper. Their first White Paper, "*Standardized Testing: What Youth with Disabilities Have to Say*" is available from through the KASA website or the Family Voices Catalog. - <http://www.familyvoices.org/catalog/php>.

## NEWS FROM OUR PARTNERS



**Healthy and Ready to Work** is happy to announce the forth call in a series—Integrating Health-Related Needs into Individualized Education Plans and 504 Plans. This call is scheduled for this Friday, October 26, 2007, from 3-4PM ET/ 2-3 PM CT/ 1-2 PM MT/ 12-1 PM PT/ Alaska 11 AM-12 PM/ Hawaii 10-11 AM. Speakers are: Cecily Betz; Stan Handmaker, Beth Swedeen, and Bridget Via. For more information including a list of learning objectives, please visit HRTW U - <http://www.hrtw.org/hrtwu>



Safer Health Care for Kids, a program of the **American Academy of Pediatrics**, is a program designed for physicians, allied health professionals, administrators, parents, and caregivers, and features a new Web-based resource center for pediatric patient safety information and strategies. Visit [www.aap.org/saferhealthcare](http://www.aap.org/saferhealthcare). Here you will find patient safety tips, valuable information links, and expert advice on ensuring the safety of care children receive in all health care settings. Plus, you can download any of the free archived webinars on topics such as Medication Safety in Ambulatory Care, Hospitalists as Safety Intervention, and Safety Rounds in Ambulatory and Inpatient Setting. Be sure to register for the next live webinar—Racial/Ethnic Disparities and Patient Safety, Thursday, November 15, 2007, 12:00–1:00 p.m. ET. Registration Deadline: November 14th. For more information or to register visit: <http://www.aap.org/saferhealthcare>

## Family Leadership in the States, *continued*

### ♥ What's Happening in Family Voices Region II

Many exciting initiatives are taking place in Family Voices Region 2 (New Jersey, New York, Puerto Rico and Virgin Islands). In **New York**, a parent leadership group and youth group are working together with KASA (Kids as Self Advocates) youth providing input on transition. Recently, the Youth Advisory Council met with the youth leader group and parents, supported by funding through an Integrated Community Services grant. Youth leaders were recruited statewide through youth groups, counties, and parent agencies. Parents were added to Family Champions and were asked to share their experiences with and information on transition. A transcript of all the proceedings was prepared, and New York now has great information to share. One of the participating young adults was 100% deaf and used the CART services.

In **Puerto Rico** the Title V Committee, including representatives from the CYSHCN program/Health Department, the Governor's office, Center for Independent Living and Family Voices PR, is exploring how they can provide workshops for medical professionals and students who are going to be doctors regarding children with disabilities so they understand the issues faced by children and families. NJ SPAN, home to Family Voices NJ and the NJ Family to Family Health Information Center, has shared information about their Medical Student Education Project with PR. Family Voices PR continues to work "to get the word out" regarding CYSHCN, most recently via the radio!

In an earlier edition of Friday's Child we reported that **New Jersey** SPAN was selected by IBM to participate in its ¡TradúceloAhora! translation program. This grant program uses a special, enhanced version of IBM WebSphere Translation Server software with added functionality and refined translation capacity to translate web sites and email from English to Spanish for schools and community organizations. One exciting outgrowth of this support occurred this past month. A parent whose daughter has significant health needs and who often has to wait in the emergency room for as much as six hours used one of SPAN's forms to get her doctor to write her a prescription for a sign language interpreter for her daughter and a Spanish interpreter for her. She went to the emergency room, showed them the prescription from the doctor, and within 10 minutes had both a sign language and Spanish interpreter working with her!

### ♥ Navigating the System: The IEP and U: No Parent Left Behind

**Bruce Orr, Family Voices DE**, has developed an inaugural workshop that is sure to empower parents and grow their level of participation in the IEP process. This workshop teaches: (1) strategies to support parents in being confident participants in the IEP process; (2) how to get support from the educational system when developing and setting goals for your child; and (3) how to write an IEP Vision Statement for your child. Orr, an advocate for children and families with more than 20 years experience, launched this workshop in September 2007 in DE. Bruce's vision is to "take it on the road" and share this workshop with other parents and caregivers. To learn how you may include this training in an upcoming event, please e-mail Bruce at [BruceOrr@AbilityAdvocates.net](mailto:BruceOrr@AbilityAdvocates.net)

## OCTOBER IS



Visit: <http://www.accessexcellence.org/HHQ/HRC/HF/>

## NEWS FROM OUR PARTNERS



The Planning Committee for the 2008 National EHDI (early hearing detection and intervention) Meeting has announced that the due date for abstract submissions has been extended until November 1, 2007. Please help make this the best EHDI meeting ever by submitting an abstract related to what you are doing to improve EHDI programs. Details about abstract submission can be found by visiting the National Center for Hearing Assessment and Management (NCHAM) at <http://www.infantheating.org/> and clicking on the button for the 2008 EHDI Meeting.



## The Family Voices Store at Family Café— One Stop Shopping for Family and Friends



Looking for a way to honor a family member or special caregiver, or seeking just the right thank you gift? Consider making contributions to Family Voices through secure, on line donations, purchases of Family Voices Merchandise at [www.cafepress.com/shopfv](http://www.cafepress.com/shopfv) or purchases from Amazon.com through the link on our web home page. Simply visit our website, <http://www.familyvoices.org>, to make a donation or to learn more about how financial gifts are used. Donations may be sent directly to:  
**Family Voices**  
2340 Alamo SE, Suite 102  
Albuquerque, NM 87106.



## News You Can Use: Resources and More

### ☑ Opportunity for Dental Forums for CYSHCN

The Association of State and Territorial Dental Directors (ASTDD) is offering states one more opportunity to hold a Dental Forum addressing the needs of children and youth with special health care needs and to develop a state plan. "ASTDD is pleased to announce another RFP for State/territorial forums for SCHCN ([http://www.astdd.org/docs/2007fallRFP\\_CSHCNforum.doc](http://www.astdd.org/docs/2007fallRFP_CSHCNforum.doc)). Proposals are due electronically to [bev.isman@comcast.com](mailto:bev.isman@comcast.com) by November 15, 2007." If your state has not already held one, this is your chance! Many different applicants have received the funds, including Family Voices! And there are many who could provide information if you decide to undertake this. For more information, visit the ASTDD website at <http://www.astdd.org> (see the second bullet).

### ☑ Announcing: The One Application

At the Family Voices Conference in Washington in May 2007, Adrienne Akers made a presentation about the Universal Application System/Utah Clicks that many attended. This web-based universal screening and application system was specifically designed to make it easier for families to find and apply for your state's health, human and work force services through a user-friendly, streamlined process. The system is now called The One Application and is available to other states through Dynamic Screening Solutions, Inc. The powerful eligibility module screens clients for services and benefits while allowing for flexibility across multiple state agency requirements. Happy customers and reduced administrative costs offer an immense value to states. Click here to take a brief online tour of The ONE Application. Your comments and questions are welcome. You may also schedule a more in-depth, interactive online demonstration for you and your colleagues at your convenience and at no cost. For additional information, also visit <http://www.go-dss.com>.

### ☑ CATCH Residency Training Grants: 2008 Call for Proposals

The Community Pediatrics Training Initiative (CPTI) is teaming up with the Community Access to Child Health (CATCH) Program for the 2nd year to provide a grant opportunity targeting **pediatric residency training programs**. The mission of this program is to provide support to residency programs to build sustainable opportunities for residents to gain experience working on community-based child health initiatives that increase access to medical homes or specific health services not otherwise available. Grants up to \$12,000 will be awarded on a competitive basis to pediatric residency programs that submit proposals to plan and implement community-based child health initiatives as part of the training curriculum over the course of 16 months. A pediatric faculty member must oversee the project and provide mentorship for residents participating in project activities. The 2008 Call for Proposals and Application is now available online. Proposals are due by no later than **4pm Central on November 16, 2007**. For more information, please send questions to: [cpti@aap.org](mailto:cpti@aap.org).

*"Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, 'I will try again tomorrow.'"*

-- Mary Anne Radmacher