



Zoe Rose Memorial Foundation hosts Inaugural Preemie Parent Summit

On October 22nd and 23rd, twenty-seven parents, representing 24 different preemie parent support organizations, met in Atlanta, Georgia for the 2010 Preemie Parent Summit. The event was hosted by the Zoe Rose Memorial Foundation through a grant we received this summer. The groups met to share best practices and engage in discussions about how each group could further their initiatives and create a collective voice for parents of preemies.

The summit began with brief introductions by each attendee which included their story as a parent of a preemie and the mission of their own advocacy efforts or support organizations. This was then followed by a presentation by Deb Discenza, co-founder of [PremieWorld](#), about utilizing technology to help your organization. She discussed an array of topics including how to leverage social media, how to create an intranet and the importance of doing so and how to use technology to increase efficiency of communications among your organization's members. She also described several sites that each organization could utilize for document sharing and survey creation, such as [surveymonkey.com](#), [verticalresponse.com](#), [box.net](#), [basecamphq.com](#), and [hootsuite](#).

The technology presentation was followed by a presentation by Karen Moore, CEO of [Moore Consulting](#) in Tallahassee, Florida about marketing and fundraising on a "zero" budget. Karen gave us all a crash course in both topics and covered the importance of branding, networking and PR. She specifically gave us tips on how to get our message out to the public at large with goals for each quarter, including public service announcements at least once per year, letters to the editor four times per year, submitting op-ed pieces once a year, hosting special events each quarter, and speaking at civic organizations once a month. Karen also gave useful information with regards to fundraising, which she calls "friendraising".

The summit then moved on to panel discussions surrounding the topics of "events & community projects," "pr & fundraising," and "education." Three or four attendees detailed the successes and strategies of specific programs their individual organizations utilize. Following are the individuals who spoke:

Events/Community Projects:

- Mary Beth Hazelgrove, executive director of [Premies Today](#), spoke about their holiday parties, holiday cards (including Mother's Day & Father's Day), as well as their educational lecture series they do covering conventional and non-conventional therapies and treatments
- Kelly Fraasch, president of the [Parent Resource Network](#) in Pittsburgh, presented their unique case in a city with six hospitals that do not have good relationships with one another. She was able to leverage their competition with one another to get a representative from each hospital to sign an agreement for parent support services



through Parent Resource Network. They are completely staffed by volunteers and do not receive any funding from the hospitals.

- Becky Hatfield, Parent Support Specialist in Utah, spoke about their bedrest support program called “Bed Buds” where they host a lunch each week for the moms on bedrest in the hospital. They also have weekly survivor bead meetings for both the bedrest moms and the parents in the NICU whereby the parents create necklaces out of beads that are color coded to different NICU specific procedures and milestones.

PR/Fundraising:

- Kelli Kelley, executive director of a [Hand to Hold](#), shared the importance of diversity amongst an organizations advisory council and Board of Directors noting that they utilize the expertise and talents of local business leaders, nurses, physicians, therapist, and social workers. She expressed an interest in collaboration amongst groups to avoid duplication and “re-creating the wheel”. She also shared information about their signature event called “Premie Power” which is a photo and essay contest of comparing your baby to a superhero. The entries will be judged by local celebrities in Austin, Texas and the winner will be announced at an event where all attendees, nurses and doctors included, will come dressed as superheroes. This will all be done during November for Prematurity Awareness.
- Nick Hall, president of [Graham’s Foundation](#), presented their unique NICU care packages which can be requested at no charge through their website. He noted the importance of picking one thing and doing it well! He also spoke about the importance of networking due to the relationships he has made with suppliers (Kodak, Vodka, Hotel Co., etc) that end up adding to the care packages and their territory to cover with increased demand.
- Kara McBurney, Community Director at the March of Dimes in Kansas City, Missouri, spoke about the importance of including a mission piece along fundraising efforts so that donors know specifically where their money will be going and how it will be used. She also spoke about creating specific sponsorship proposals based on the demographics of the area you are hitting.
- Kristie McNealy is a medical writer, mother of a preemie, and blogger who had an interesting take on fundraising given that her husband is a third party candidate for congress in Colorado. She spoke about the importance of personalizing your fundraising efforts by hand addressing and signing mass mailings. She noted that a personal visit or phone call for local donors will help maintain loyalty as will holding a dinner for top donors. Kristie also mentioned investing in a professional fundraising letter writer who works on commission as money well spent as the writer is motivated by that commission.

Education:

- Ariel Dogget, an RSV advocate, shared her personal story about the effects of RSV on her son who, while born early, was not recognized as an “at risk” baby for RSV and yet contracted the disease and nearly died. She noted that she has been able to share



her son's story via various speaking engagements and through medical journals - to help further his story and her advocacy/awareness efforts.

- Cami Marsh, Common Bonds Parent Support Coordinator at Intermountain Medical in Utah, shared the variety of programs their NICU offers to support not just the parents, but the entire family. Their group offers grandparent classes to help grandparents understand what their children and grandchildren are going through when in the NICU. They also offer a sibling class called "ice cream and isolettes" where the siblings are allowed into the NICU and have a class, complete with an intubated baby doll in an isolette. They learn all about the different tubes and wires, how to take a temperature and change a diaper and when they're done they get a certificate and ice cream. This program is invaluable in easing the fears of the older siblings. They also conduct educational classes specifically in ROP, infant massage, and post partum depression. In regards to bereavement, they work in conjunction with OBs and Perinatologists to identify families who receive a terminal diagnosis for their baby during pregnancy. They meet with the family in their home and are present when the family is admitted to deliver the baby.
- Liz McCarthy, founder of [PreemieBlogMoms](#) for parents of micropreemies, among various other support groups in the Bay Area of California, presented the history behind PreemieBlogMoms, a Yahoo! Group with nearly 700 members, all of whom have babies who were born at or below two pounds. She noted that this group is a great one for surveys and research purposes and noted that her specific interests lie in the long term complications of extreme prematurity.
- Gayle Schumacher, founding member of the Parent Advisory Council at Brigham and Women's Hospital in Boston, MA spoke about how her multidisciplinary advisory council has been instrumental in educating the NICU and hospital staff about the needs of parents. By working together they have created an information booklet that the doctors and nurses can use when speaking to the parents about specific tests, procedures, or diagnoses and is always available at the bedside for the parents to read. They have also developed an extensive discharge packet and were able to convince the hospital to send their lactation nurses for NICU specific lactation training.

On the second day we began with a presentation by Becky Hatfield, parent support specialist in Utah and leader of [NPA's Family Advocacy Network](#). Becky explained that FAN is creating a database of support groups around the country that will soon be active on the NPA website. She also noted that FAN conducts monthly conference calls for support group leaders on various topics such as volunteer training, sibling programs, etc.

We ended the summit with an open forum about what we could do collectively to harness the energy from the group and continue the momentum created in collaborating with one another. The energy and enthusiasm among the group was palpable. Even in the first days following the summit I have received numerous emails from attendees thanking us for the opportunity to be a part of the summit and commitment to continue to collaborate to raise the profile of our own individual groups while simultaneously "increasing the volume" of the

voice of the parent. We were so thrilled to have the opportunity to host an event such as this and look forward to hosting a follow-up event in 2011!

As I mentioned in my welcome to the group on the first day...we are all connected because of a passion to help others that was born out of one of the most traumatic life experiences of having a premature infant and medically fragile child. It is nearly impossible to go through this and not be changed by it, likewise it is nearly impossible to go through this and not want to help others. There wasn't a single person in the room that could say they were more passionate than the person sitting next to them...we are all very passionate about this cause and we can not fool ourselves into thinking that our own individual groups can help every single preemie family around the country all by ourselves and do it well. If we all have the ultimate goal of serving and advocating for preemies and their families...shouldn't we collaborate, share our struggles and successes in an effort to better our own organizations while also creating an effective and active voice for parents of preemies? The resounding answer I heard over the course of the two sessions, was YES!



Participants from Left to Right

Back row:

Deb Discenza, Kelli Kelley, Becky Hatfield, Kellie Toothman, Lori Aston, Mike Petrucelli, Portia Beloborowski, Gayle Schumacher, Ariel Dogget, Kara McBurney, Nick Hall, Lori Buss, Susan Selby, Chris Dittman, Becky Dittman, Catherine Sylvester, Kristy Love, Mary Beth Hazelgrove, Judy Bender

Kneeling & Seated; Angie Hernandez-Yi, Kristie McNealy, Richard Sorrells, Keira Sorrells, Liz McCarthy, Kelly Fraasch, Samantha Bohnert