FROM THE EDITOR
BY JEAN HOUSE

Living with dup15q syndrome, it seems we are always moving on to the newest breakthrough and the next goal. Researchers make new, exciting discoveries. Families, doctors, therapists, and teachers are constantly planning the next steps in caring for our children. And this dynamic, fast-growing organization, Dup15q Alliance, is forever moving forward.

With a new name for the organization (formerly IDEAS) and the introduction of the registry, 2011 was a year of important firsts and new beginnings for Dup15q Alliance. This exciting trend has continued into 2012. Because springtime is all about new growth, this issue of The Mirror takes a closer look at several projects that have recently taken root and begun to blossom. Inside, you can learn all about:

• The new organization, Asociacion IDIC 15, which has recently been established for Spanish-speaking families of people with dup15q
• The first results from analysis of Dup15q Alliance International Registry data
• The new fundraising incentive program, which will reward members who meet goals for Dup15q Alliance fundraisers with registration fees and hotel stays at the 2013 International Conference
• The first patient’s visit to the new Dup15q Clinic in Boston
• The new regional and international representatives program, which will encourage members to gather together locally, offering families even more support

These new developments offer many ways for members to get involved and give back to our community. Consider hosting a gathering, organizing a fundraiser, or simply filling out the International Registry—it’s an easy but powerful way to give back to fellow Dup15q Alliance families and benefit your own family at the same time. It takes only an hour or two, but the benefits are huge.

http://www.dup15q.org
The Dup15q Alliance International Registry was developed so families could share information about their children affected by dup15q, providing a better understanding of dup15q syndrome for both families and scientists.

The data in the registry has the potential to accelerate research. As families join the registry, they are assigned a code number which preserves the confidentiality of their data. Researchers can look at this deidentified data and see how many families may be experiencing a symptom or trait that they are interested in focusing their research on. Researchers can contact the registry coordinator, who will inform families of research projects that may be of interest to them. The researchers will not have access to any identifying or contact information for families.

We want to extend a huge thank you to the 78 families who have already completed the registry survey. As you can see, these families represent children affected by both isodicentric 15q and interstitial duplication 15q. Also, many families have children affected by other rare variants of dup15q.

Already the registry is yielding information that is helpful to both families and researchers. For example, we now have updated statistics on the percentage of children with dup15q that experience seizures.

When families complete the registry, they are given access to the full range of data collected in the registry. This information can be helpful for doctors, specialists, therapists, teachers, childcare providers, and other family members.

**Have you filled out the registry?** Dup15q Alliance would like to double the number of registry respondents by June, 2012. That means we need another 80 families to gather their children’s information and invest about an hour in completing the registry. The payoff for you will be immediate access to the registry data as soon as your survey is complete. The payoff to the dup15q community is richer data for families and scientists. If you do one thing for Dup15q Alliance this year, please do this. Every response moves our understanding of this chromosome abnormality forward.

The Dup15q Alliance International Registry was made possible by the generous donations of friends and family from Dup15q Alliance.

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**Table: What is the affected person’s chromosomal diagnosis?**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Response Percent</th>
<th>Response Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isodicentric 15q</td>
<td>67%</td>
<td>52</td>
</tr>
<tr>
<td>Interstitial Duplication</td>
<td>15%</td>
<td>12</td>
</tr>
<tr>
<td>Interstitial Triplcation</td>
<td>1%</td>
<td>1</td>
</tr>
<tr>
<td>Micro Dup15q</td>
<td>3%</td>
<td>2</td>
</tr>
<tr>
<td>Mosaic Isodicentric 15q</td>
<td>3%</td>
<td>2</td>
</tr>
<tr>
<td>Mosaic Interstitial Duplication/Triplication</td>
<td>1%</td>
<td>1</td>
</tr>
<tr>
<td>Unsure</td>
<td>8%</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>2</td>
</tr>
</tbody>
</table>

Total Respondents: 78

**Table: Has the affected person ever had seizures?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Response Percent</th>
<th>Response Total</th>
</tr>
</thead>
<tbody>
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<td>No</td>
<td>44%</td>
<td>34</td>
</tr>
<tr>
<td>Unsure</td>
<td>9%</td>
<td>7</td>
</tr>
</tbody>
</table>

Total Respondents: 78
My son, William, is a wonderful 8 year old with dup15q. He began suffering absence seizures at 5 years of age. His neurologist was able to control them with medication for two years; however, in September 2010 William’s seizures began to come in an assortment of types at increasing frequency. When local resources were exhausted, we decided to travel to specialists out of state for a fresh and comprehensive evaluation.

William received a full two-day video EEG, and our initial consultation went well, but collaborating with that particular facility quickly proved to be intolerably slow and difficult. Just as we were feeling our most desperate, we were able to schedule William to be the first patient of the new Dup15q Clinic at Massachusetts General Hospital in Boston!

We stayed two short blocks from Dr. Ron Thibert’s office, and our hotel had an outdoor swimming pool (to William’s delight). The night before the appointment, we were given an impromptu tour of the Beacon Hill Fire Department just across the street. William even got to wear an actual Ladder 24 helmet!

Prior to the visit, we coordinated with Dr. Thibert to figure out what specialties we were in need of while we were there. For this visit, we only wanted epilepsy support. When we arrived, Dr. Thibert met us personally and conducted a thorough history and exam. We then checked into the hospital for a 24-hour EEG. The hospital staff was skilled in dealing with William and wanted to do whatever they could to make our stay as easy as possible. William enjoyed the attention and thought his gauze helmet covering the EEG leads was hilarious!

One of the nation’s experts on epileptic spasms, Dr. Elizabeth Thiele, was able to consult and diagnose William as suffering from these. We have dropped one medicine of the four he was on, and that change alone has helped lower the number of seizures and spasms he has daily. As I write this, William is on week one of the low glycemic index therapy diet. Heidi Pfeiffer, a registered dietician in Dr. Thibert’s office, is helping us convert William to this way of eating to achieve better seizure control, which we hope will allow further reduction of medications.

We’re looking forward to seeing all the other doctors the next time we make the trip. Dr. Thibert has about five different doctors already lined up, but I am sure the clinic would be helpful with looking for a Mass General option if a patient is seeking a specialist other than those already involved.

We are fortunate that Iowa Medicaid is able to provide financial assistance with travel, hotel, and meals for the patient and one caregiver when going to appointments outside our county. Be sure to investigate what resources might be available to help cover the costs of a trip to this exciting new Dup15q Clinic. As patient number one can attest, it is certainly a Center of Excellence for our kids!
The New Fundraising Incentive Program

By Mike Porath
Fundraising Committee Chair

Fundraising for Dup15q Alliance is off to a great start in 2012. We set an ambitious goal to raise $100,000 this year and in January alone more than $20,000 was raised. Contributions that came in after the year-end ask helped, as well as the “Believe” concert in Massachusetts, where 12-year-old Nelson Barnett inspired his fellow musicians to rock out for his brother, Roland, and all those affected by dup15q syndrome. Thank you, Nelson!

To hit our goal, we need a lot more Nelsons. One way we hope to encourage members to host a fundraiser is to reward those efforts by offsetting costs to attend the 2013 International Conference in Minneapolis. Based on the amount of money you raise for Dup15q Alliance, you may earn registration and one or more nights at the hotel:

- $1,000–$2,499: one free registration at the 2013 conference
- $2,500–$4,999: two free registrations
- $5,000–$7,499: two free registrations and one free night at the hotel
- $7,500–$9,999: two free registrations and two free nights
- $10,000+: two free registrations and three free nights

There are a few guidelines for this incentive program:

- E-mail info@dup15q.org to register your fundraiser
- Get at least 10 contributors to donate to your fundraiser
- The program runs through the end of this year and is not mandatory
- You can still participate without organizing and hosting an event. If you attend another dup15q fundraising event and 10 people contribute to that fundraiser on your behalf, you’re eligible
- If multiple families are holding an event jointly, then the rewards for the amount raised will be split among the families
- All donations are to be directed to Dup15q Alliance, either through mail, online, or through a www.firstgiving.com webpage

Please check out www.dup15q.org for fundraising ideas. Questions? Ask me: mikeporath@yahoo.com. And please consider helping Dup15q Alliance. This is a critical year for our growing organization, as we are working to fund the registry, promote research, support families with dup15q, and prepare for the 2013 International Conference. If you have the desire to hold a fundraiser, we’ll help you pull it off.

Financial Report: End of Fiscal Year

By Tom Doyle
Financial Officer

2011 was an exciting year for us. We changed our organization’s name from IDEAS to Dup15q Alliance to provide a clearer picture of who we are and of our mission. We participated in the best attended conference in our history in Philadelphia. And we started the new registry, which will provide great information for all our families.

As of the end of the fiscal year, the balance sheet indicates that we have $25,494.90 in our checking account and just under $262,000 in our money market accounts, for a total of $287,718.89 current assets. Because of the costs of the initial setup for the registry, the total of our assets is down about $16,000 from the end of the year last year, but your generous donations throughout the year helped us to cover much of the registry cost without digging deeper into our savings. Thank you!

If you haven’t already, please help us make the registry a valuable tool for Dup15q Alliance by setting a new year’s resolution to complete the registry process for your family. The board has completed the process of setting a budget for the coming year, and we are excited about the possibilities for 2012!

We continue to be grateful to the many volunteers who make Dup15q Alliance work and to our families who so generously support our efforts. On behalf of Dup15q Alliance, thank you for all of your support, encouragement, and participation throughout the year. The bar is set high for 2012!
ORGANIZING A FUNDRAISING TEAM
BY TESSA AND MIKE QUINLAN

In September 2009, our son, Gavin, who was 5 at the time, was diagnosed with dup15q. We knew nothing about the syndrome, but we did know we wanted to move forward. We realized that his genetics wouldn’t change, so we asked ourselves how we could help our son now and in the future. After much research, meeting with other parents of children with the syndrome through the Parent Match program, and educating ourselves on how we can help, we took on the challenge of a fundraiser.

We gathered our immediate family members, which included our parents, our siblings, and their spouses. We gave them materials including the flyer announcing the fundraiser, an IDEAS (now Dup15q Alliance) brochure, and a letter informing businesses and individuals why we were asking for donations. Each person was prepared with all these materials when approaching potential sponsors and donors, so they knew we were legitimate and meant business.

Our first annual GQ Fundraiser was wonderful: we raised $6000. As proud as we were, we wanted more, so in October 2011 we held our second annual fundraiser. We again gave ourselves a few months for preparation, which is something we will change next year, when we add more time, but we worked hard and got the job done. What did change in 2011 is what we requested of volunteers at our family fundraiser meeting. They had all the materials to distribute, but this time we assigned each person at least five places they already frequented, so they didn’t feel they had to go out of their way to solicit. If they wanted to do more, they could.

So what was different this year? All of our family members stepped up their games. We were more proactive getting the word out via Facebook, BigTent, and many e-mails to friends and family members. We even did a mass mailing through the U.S. postal service to people who don’t generally use online communications. We left no stone unturned. In 2011, our planning and hard work paid off: we raised more than $11,900 for Dup15q Alliance! We are very proud that we tackled this task and look forward to 2012.

Tessa and Mike are the parents of Gavin, 7 (dup15q), Ava, 4, and Addisyn, 1. This is the first in a series of articles about the Quinlan family’s experiences organizing the GQ Fundraiser.

Announcements

Awareness Products at the Store
Mother’s Day is around the corner! Purchase a Dup15q Alliance cause bracelet for Mom or any woman who is affected by dup15q. The store offers many other awareness items, such as blue silicone bracelets, shirts, sweatshirts, and awareness pins. Visit www.dup15q.org/store.html to order your items today. All proceeds benefit Dup15q Alliance.

Company Match
As we begin this new year, we are asking our friends and families to inquire with their employers whether they have a gift-matching program. Many companies do, and this is “free” money for Dup15q Alliance to help us accomplish our goals. We can assist with the necessary paperwork, if needed. Thank you. Together we can make a difference!
MEETING IN Italy

BY LORENZO CERUTTI

During the first weekend of September 2011, the third Italian Dup15q Family Meeting was held in Prato, near Florence. Almost 20 families came from all over Italy, from the extreme north to the deep south. On Friday night, we spent the evening dining together, met with old friends, and greeted new families whom we had communicated with only by e-mail before. We all were accommodated in an ancient cloister: it was spacious and tranquil.

On Saturday, dedicated staff specifically hired for the event spent all morning playing funny games with all of the children. At the end of the morning, a great lunch energized everybody for the afternoon, when a small troupe performed a wonderful show for the kids. We have had wonderful help from volunteers every year. They really love us, and we can never thank them enough for the relief they give to our families.

Meanwhile, the parents spent all day at the conference meeting. We talked with an Angelman syndrome specialist about a project to create a focus point in Italy for medical treatment and therapy for our children who have dup15q. (Angelman is also associated with the fifteenth chromosome.) Also, we talked about school and the future with a professional who directs a community where people with disabilities can spend the day working and playing together.

Additionally, we learned about an Italian biobank for genetic tissues and sending blood samples to Corriel Institute. Together with Dr. Beghi, who chairs the Italian Epilepsy Association, we discussed our Italian epidemiological research project and the way to conduct it during the two years. The goal is to develop a protocol for all Italian pediatricians so they can recognize dup15q syndrome symptoms more quickly.

Finally, two fathers who had attended the conference in Philadelphia presented a summary of highlights to families. Throughout the day, a professional photographer took many pictures of each family, to preserve memories of this special occasion. It was a great day, and at the end we all were very satisfied—and very tired.

On Sunday morning, a psychologist who works with siblings of children with special needs talked with us about resiliency and relationships. Later, when it was time to say goodbye to all of our friends, we left feeling stronger to deal with everyday routines, difficulties, sadness, and happiness. We are not alone: we can help each other. In one word, we are a family!

I want to thank two parents who did an incredible, huge job for the meeting and overall for our association, nonsolo15: Christine Reimann, the president of nonsolo15 and mother of Fabio, is our lighthouse, and Francesco Jannon, the vice president and father of Luca, has energy and optimism like I’ve never found anywhere else.

We’ve now started to work on our next conference, which will be held in September 2012. We will focus on fun, rest, entertainment, and happiness. There will be even more time spent together.

I want finally to send hugs to all of our U.S. friends. Through e-mail, the Dup15q Alliance website, BigTent, and Facebook, they have shared their friendship. Thank you all for the fantastic job, including the registry, you are managing for all of us. I really hope to see you soon, maybe here in our wonderful Italy.
As we begin the new year, I am happy to report on a new group, Asociacion IDIC 15, which is in the final stages of being created to support the particular needs of speakers of Spanish. While the group is being incorporated in Spain, its reach extends to any families whose first language is Spanish, regardless of their country of residence. Asociacion IDIC 15 will share the same core values as Dup15q Alliance while reaching out to Spanish-speaking member families who do not communicate in English as their primary language or need to address their needs for information, support, or services with local resources in countries where Spanish is the primary language. The group, which is incorporating as a nonprofit organization, held its first general membership meeting in February.

How it Began
As summer 2011 began with the conference in Philadelphia, two families who were new to Dup15q Alliance were just getting started connecting. Despite knowing little at the time about this organization, both families attended and experienced a crash course on what it means to be a member of the dup15q family. After years of being misinformed and even misdiagnosed about their children’s rare chromosome disorder, they had quite a bit of information to digest in just three days! Ever hear the expression “drinking from a fire hose”? That is how these two couples—Quino and Marta Renovell, and Miguel Angel Orquin and Natalia Conejero—felt. Quino and Marta are the parents of three children, including Lucas, 3 (dup15q), and Miguel Angel and Natalia have two children, including Mara, 8, (dup15q). Both families went to Philadelphia with big ideas and hopes. Soon after their return trip home, they put their hearts and minds to work toward improving the experiences of other Spanish-speaking families. Their first goal was to sign up 20 new families by December 31, 2011. By mid-October this objective was already accomplished! On October 16, Miguel Angel, Quino and I, along with two other new families, met in Valencia, Spain, for the first time. While the meeting was informal, we all connected with one another and began to forge new friendships that are sure to last for many years! The first discussions regarding the creation of the group began at this October meeting, and since then we have been keeping close contact with Patti Rubel and Kadi Luchsinger, members of the Dup15q Alliance Board of Directors, to talk about short-term ideas such as getting registration forms translated into Spanish and otherwise helping new families become aware of dup15q and the registry, which is planned to become available in Spanish this year.

Leaders and Their Roles
Quino is a business professional who understands the power of working together as one organization to reach a common goal. Miguel Angel is a passionate, enthusiastic father and a medical student whose mission in life is to put the scientific method to work to find viable treatments for this chromosome disorder. Francisco Arjona, who joins us from Malaga, brings to the group his unique computer skills. He has designed a website that is not only informative but created with adaptive links suitable for use by disabled individuals! My role in the organization is to help in coordinating next steps and bridging any cultural differences, as I plan to have a foot in Asociacion IDIC 15 as well as Dup15q Alliance.

Challenges and Opportunities
At its core, the mission and vision of Asociacion IDIC 15 is, and always will be, to support Dup15q Alliance in all of its endeavors. That being said, it remains to be defined how to connect and coordinate the activities between the groups. By definition, every family registered in Asociacion IDIC 15 has the right (and the choice) to enroll in Dup15q Alliance and the International Registry. As mentioned earlier, many of the new tasks that Asociacion IDIC 15 plans to undertake are intended to support new families to identify academic, professional, and family resources in their language or local setting. As a group in its early stages, the early membership meetings will define the first tasks. There is more to come about this exciting new group. Please read The Mirror for future updates!

Adios y Muchas Gracias!
To connect families and inform them of regional information and events, Dup15q Alliance recently created 10 national and three international regions (additional international regions will be created soon). A representative has been assigned to each region and will keep families informed of upcoming events, gatherings, and fundraisers. Regional representatives will also reach out to new families and be available for all members who are in need of emotional support. You may receive e-mails from your representative, so please keep a look out for those. Also, if you are interested in hosting a gathering or fundraiser or have any questions, please contact your regional representative. Information about the regional representatives can also be found on our website, www.dup15q.org.

**U.S. Regional Representatives**

**Region 1:** ME, VT, NH, MA, CT, RI  
Joanne Poore

**Region 2:** NY, PA, NJ  
Kadi Luchsinger

**Region 3:** VA, DE, MD, DC, WV, KY, NC  
Patti Rubel

**Region 4:** OH, IN, MI  
Rylie McHam

**Region 5:** IL  
Shannon Rozovics

**Region 6:** WI, MN, IA, MO, ND, SD, NE, KS  
Todd and Katie Supina

**Region 7:** AK, WA, OR, ID, MT, WY  
Colleen Lowell

**Region 8:** CA, HI, NV, UT, CO, NM, AZ  
Sarah Porath

**Region 9:** TX, OK, AR, MS, LA  
Postion open. Please e-mail info@dup15q.org for more information.

**Region 10:** FL, AL, GA, SC, TN  
Dana Tilton

**International Regional Representatives**

**Canada:** British Columbia  
Lori Eisenhauer

**Canada:** Manitoba and Saskatchewan  
Denis Myers

**Canada:** Eastern  
Ellen Doxator

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**How to . . .**

**Go Paperless**

If you would like to receive your copy of *The Mirror* via e-mail rather than through the mail, please visit www.dup15q.org/Mirror.html to sign up for the newsletter online, or send an e-mail to admin@dup15q.org.

**Update Contact Information**

Don’t miss out on messages from Dup15q Alliance. Please e-mail any changes to phone numbers, mailing addresses, or e-mail addresses to info@dup15q.org.

**Buy Dup15q Alliance Items**

Check out the store at www.dup15q.org/Store.html, where you’ll find a limited number of conference binders, new awareness cards, and much more.

**Write for The Mirror**

Do you have a story to tell? Share it with other members of Dup15q Alliance! We are accepting article submissions for upcoming issues of *The Mirror*, including Reflections from a Sibling, Reflections from an Extended Family Member, and the Family Portrait. We’re looking forward to hearing from parents, brothers, sisters, uncles, aunts, cousins, and grandparents. Even if you have just enough time to jot down a couple of sentences, you can contribute to your newsletter. We often ask a question via BigTent; members’ answers appear in the Family Favorites feature. For more information about writing for *The Mirror*, contact Jean House at jean@editorhouse.com.
In Memoriam:

SAM O’DONOVAN

BY ANGELA O’DONOVAN

We are an Irish family of four living in Wimbledon—myself, Angela; my husband, Frank; and our sons, Sam (dup15q) and Rory. Our beloved Sam died on December 16, 2011, at age 18. His death was sudden and unexpected, and we still don’t know the cause. Sadly, it seemed Sam was one of the more affected individuals with dup15q, with six copies of the chromosome material.

Sam was a much loved son and brother, a quiet and gentle person. From the moment he came into our lives, he took us over and life changed for us in new and different ways.

Sam loved to be free: out of his wheelchair, able to move about and explore as he pleased or simply to relax. He loved water, both the sound of running water and being in his bath. Hydrotherapy and swimming were two of his most enjoyed activities. It must have been wonderful for him to move freely and weightlessly in the pool or just to feel the warm water.

While Sam could not communicate very much, he could show great determination and willpower and could be very clear in his choices. We could also see when he was relaxed or anxious even if we did not know why. One thing that was always clear was that home, particularly his own room, was his “safe place” where he would visibly relax when coming in from the outside world.

Sam’s story is one of four; as a family, we have each been affected and come through this in our own ways. Sam has made me the person I am today. Our family life is not typical; it can be eventful and very unpredictable. We have met some wonderful people over the years, made great friends, and enjoyed support from good neighbors.

Sam’s funeral Mass was on the morning of Tuesday January 3, an exceptionally wet, stormy day. Rory read one of the Old Testament readings, so beautifully for his special brother, and made us very proud. We are devastated and lonely for Sam, but he is now at peace and will live on in our hearts forever.

Angela Nugent O’Donovan would be very happy to hear from other parents via e-mail or Facebook. You can find her via Facebook.
Rhythm sounded. Harmony blended. And a deposit of almost $9,000 ch-chinged! With 33 bands, the first-ever rock concert to benefit Dup15q Alliance blew the roof off the joint on January 13 and 15 in Needham, Mass. Nelson, my oldest son, an electric guitarist who performed with two bands at the concert, was determined to make this happen. His brother, Roland, was his inspiration.

Nelson is part of Plugged-In, a nonprofit teen rock band program that teaches youth musical skills while stressing the importance of giving back to the community. They have three benefit concerts a year, and all the students vote to choose the organization for which the concert will raise money. Recently, Nelson presented a persuasive and heartfelt pitch to his fellow Plugged-In musicians and won the vote for all of us.

In October 2011: The Plugged-In musicians got an opportunity to vote for their various charities at a Community Engage evening. Thirteen musicians presented bids. When it was Nelson’s turn to present, he displayed his homemade poster with a picture of him pushing Roland in his Convaid stroller and then began speaking to the noisy crowd about his brother. The entire room full of adults and very rambunctious adolescents soon became silent as they began to listen to his every word.

Nelson talked about the rare occurrence of this particular chromosome disorder. He explained the severity of Roland’s profile: being nonverbal, frustrated, anxious, behaviorally challenged, and constantly interrupted by daily seizures. Nelson, who is often witness to the occasional awkward, inappropriate, and stressful situations that occur during outings with Roland, called on his fellow musicians to support Dup15q Alliance as a means to promote awareness and recognition of people with disabilities. In closing, he mentioned that Roland’s ninth birthday would fall within a week of the concert.

“The brother doesn’t understand the concept of a birthday party, but he loves listening to music,” Nelson said. “A concert in his honor would be a very special way to celebrate him.” The presentation ended with a roar of applause.

When the final vote was tallied, an overwhelming amount of ballots selected Dup15q Alliance as the recipient of the Plugged-In benefit concert! “It was a lesson to me about love,” commented another musician’s father, who was present at the Community Engage evening.

Sandra Rizkallah and Tom Pugh, co-founders of Plugged-In, have been organizing trice-annual benefit concerts for the past 10 years. When Sandra told us that they typically raise $3,000 from these concerts, our eyes lit up. Not wanting to come in below average, we brainstormed various ways to meet that goal. First, we set up a do-it-yourself online fundraising service, www.gofundme.com/believe, and contacted friends, family, and fellow Dup15q Alliance members. Within the initial four weeks of our efforts, we met our goal. Then we sent out press releases to local media and watched our numbers continue to rise.

At the end of December, Plugged-In offered a song-writing workshop for interested musicians to learn how to write original compositions and record a CD. Len Poore, Dup15q Alliance board chair, spoke to the musicians about dup15q syndrome, accompanied by his wife, Joanne, and their 21-year-old daughter, Lisa (dup15q). He explained what Dup15q Alliance does to support families and encourage research with the money that is raised. Along with his presentation, he showed a slide show that included photos of various children with dup15q from around the world. The music composed that afternoon was heavily influenced by the Poores’ visit and the students’ newly acquired knowledge. Songs on the CD include “In Love With Your Sound,” “Don’t Listen (You’re Not Alone),” and an instrumental entitled “Drop 25,” which relates to seizure activity. Anya Olsen, who wrote the lyrics and sang “In Love With Your Sound,” remarked how inspired she was by meeting the Poore family. “It was an amazing experience making music for something that actually mattered,” she said. The songs were recorded and professionally mixed, and CDs were sold at the concert.

We received media recognition from a couple of papers, including a write-up in the Boston Globe arts section the day before the concert. A large photo of Nelson and Roland ran with the article “Brother’s Love Strikes a Chord.”
Nelson Barnett, 12, persuaded his fellow musicians to dedicate a fundraiser to Dup15q Alliance. He played in two bands and helped compose music for the event.

The concert was incredible—and incredibly loud and long! The three song-writing bands performed live versions of their original tunes. More than 100 musicians performed and approximately 350 people attended both nights. What was even more incredible was the gathering of five Dup15q Alliance families from Massachusetts who were meeting for the first time. Instantly, we all became best friends. Roland was home in bed during the concert, due to increased seizure activity, but Nelson’s band still sang “Happy Birthday” to him as only rock stars can do. It was truly an inspiration to see everyone rocking out for our kids and Dup15q Alliance!

Nancy and Gordon Barnett are the parents of Nelson, 12, Roland, 9 (dup15q), and Maya, 4. If you couldn’t be at the show, you can still experience this special event and support the cause. Visit the Dup15q Alliance Big Tent forum, find the message “Believe’ Concert T-Shirts and CDs are on Sale,” and follow the links to place your order!

Cheers to Our Volunteers!

By Len Poore

Nelson Barnett is our volunteer of the quarter. In October 2011, Nelson asked the Plugged-In musicians’ group, which is based out of Needham, Mass., to dedicate benefit concerts to Dup15q Alliance.

Nelson, 12, has a 9-year-old brother, Roland (dup15q). Nelson prepared a speech, stood before all the other band members, and explained his brother’s diagnosis and Dup15q Alliance. Normally, the room has some chatter during presentations, but it went silent as Nelson made his speech. After the voting, Dup15q Alliance was selected as the charity that Plugged-In’s performance would benefit.

At the concert, Nelson performed with Meg ‘n’ da Know Skoolerz (Meg is the keyboard player and the other musicians are his home-schooling buddies). He also played with a band formed during a Plugged-In song writing workshop. Nelson was a contributing musician on the song “In Love With Your Sound” and also wrote and composed “Drop 25” with other musicians. Three songs from the workshop were composed and recorded. They were performed live. The “Believe” concert raised $10,000.

Dup15q Alliance thanks you, Nelson, for your courage and hard work on behalf of your brother and Dup15q Alliance.

Correction

Two names were omitted from the “Cheers to Our Volunteers“ feature in the Fall 2011 issue of The Mirror. Franny Mackling and Rae Wertz are dedicated members of the Sunshine Committee. Thank you for your service to Dup15q Alliance!
Join BigTent Today!

Please join BigTent today! BigTent is our online forum where families can connect, ask questions, learn from each other, and—last but not least—support each other.

Go to the website at www.dup15q.org for the link to BigTent. Dup15q Alliance has a restricted group, so the general public cannot join; you must be a registered family within Dup15q Alliance to read and post to the forum. This restriction is important to make the forum a safe and secure site for our families. It is imperative for you to sign up, as BigTent is our means of transmitting important information quickly to our members.

Please don’t delay; sign up today!

BIGTENT TIP

BigTent Blink: Receive a summary of news, events, and postings delivered to your e-mail.

1. Click the “Settings” link
2. Click the “BigTent Blink” link on the top of the settings page
3. Check the box next to the day you would like to receive your Blink
4. Click the “Save” button