

## **PATH Celebrates its 20<sup>th</sup> Anniversary!!**

**To celebrate PATH's twenty years of service, we have printed some heartfelt stories about the beginnings of PATH.**

**Susan Rosano, Editor**

When my daughter, Cameron, was born prematurely more than twenty years ago at Yale-New Haven Hospital, we struggled through the experience on our own. When she was a few months old, and I was contacted by a social worker at YNHH to help start a parent support group, I jumped at the chance. Surely, parents who had been through the experience would have something valuable to offer new parents.

A very diverse group of parents attended that first meeting, including Donna Levine and myself. Donna told me years afterward that she was not sure how committed I would be when I showed up with my husband and seemingly healthy baby in tow, and for my part, I was stunned when Donna listed the number of problems suffered by her son, Ari. However, that diversity set the tone for the group. When Donna's son Ari died some time later, a social worker said Donna would need to leave the group because she would frighten other parents. As it turns out, we kept Donna, to PATH's eternal benefit.

Many parent support groups develop a very narrow focus. PATH instead expanded to meet needs as they arose. After Ari's death, PATH included support for parents who lost a child and trained listeners to help. When my second pregnancy became high risk and involved extensive bed rest, PATH grew to support those mothers as well. The essential premise of PATH has been proved valid for twenty years: parents who have been through an experience have a unique ability to support others going through similar situations, and in turn become healed themselves. I am proud to have played a part in its inception

**By Carolyn Carpino, Founder**

When my daughter was born fifteen weeks early, I spent every waking moment at her isolette, going home only to sleep. Luckily, there were no siblings at home, and, I lived only 10 minutes away. My entire life became the newborn unit at Yale. While the nurses were a wonderful support system, my social interaction was with the other mothers in the unit. We began to bond and soon were pumping together, running down to bring up food for each other and crying together. During those pumping sessions, we would compare notes and talk about our feelings. Sometimes our conversations would become quite technical...since we all hung on the results of blood gases and other such tests. We would joke that we could go to a rural area and start our own newborn unit with the knowledge we had...knowledge I certainly never expected to have. When we were discharged, a couple of us stayed in contact and continued to meet and talk. A support system was born. We realized we still needed that support after the discharge for ongoing issues and also because no one else could really understand what we had been through. You had to be there to feel it. I found that I felt like an outsider with mom's that had "normal" birthing experiences, and could not really relate to them. I had watched Priests administer last rites to dying babies, dead babies in the arms of caring nurses being taken

out of the unit, people in such pain that I still shudder almost 22 years later at the memories. My baby had come back from several near death experiences and had been resuscitated in my arms. I felt so alone and isolated, and my newborn unit friends understood that feeling of being on the outside looking in. We would never be that carefree new parent with the balloons and cigars. When we actually started PATH, we did so not only for the current unit parents, but also for ourselves, to provide a forum for us to share and talk about our own experiences. Our first official PATH offering was coffee and snacks once a week in a conference room outside the unit for "drop in" support. PATH was a lifesaver for me and through PATH; I met some incredible people that I still share my life with. Lifelong friends, lifesaving friends.

**By Sandy Balayan, Founder**

My son Ari was born at Yale-New Haven Hospital in 1985 with multiple birth defects. At that time there were no Birth to Three programs or other family supports available to families of newborn infants, and after three surgeries and five weeks in the Newborn Special Care Unit, Ari was sent home under my care. I was a law student, not a medical student, but I quickly became familiar with more medical information than I cared to know. I took a leave from law school and spent my days schlepping to doctors and trying to find ways to deal with my sudden isolation with a sick baby. When Ari was six months old, I called the March of Dimes to see if I could do some volunteer work from home; they told me they were trying to get a group together to support families with babies in the Newborn Special Care Unit at Yale. Well, I nagged them a few times before the first meeting occurred, and then suddenly, I was invited to a meeting of other parents.

As I recall, there were about 6 or 8 parents at the first meeting in the Yale-New Haven Hospital NBSCU waiting room, along with the unit's social worker and a representative of the March of Dimes. The social worker and March of Dimes worker had attended a national conference of organizations supporting parents with children born prematurely or with problems. Such groups were already a happening thing in California and other parts of the West, and we decided to make it our business to have Yale catch up with the trend. We spent months discussing and trying out various programs we, felt would be helpful, creating our logo, becoming a non-profit organization, and raising some funds, with the Lapidus Foundation being our first sponsor.

We faced some resistance when a new social worker came onto the unit, but we were a strong force by then and were eventually accepted as an important resource for the unit. When Ari died at age two, working with the other parents from PATH was very therapeutic for me and PATH delicately began to include support for the possibility that some of our babies might pass away. Over time, we reached out to other hospitals, eventually creating a network across the state (even before Yale-New Haven Hospital did the same!). I am proud to have been one of the founders of PATH and pleased that I was able to find a way to channel my energy in a positive way after the loss of our son. I consider every family helped by PATH to be part of my son's legacy, and I cherish that.

**By Donna Levine, Founder**

When I was hired in Norwalk's Neo-Natal Intensive Care Unit (NICU), I started looking for an organization to help support parents who had had babies in the NICU. When my twins were born at 30 weeks, there were no services in place at Norwalk Hospital for parents of preemies. Back when they were born, I really wanted to talk with someone who had been in my shoes and could help make sense of all of the things happening to my babies. I found PATH was an already established unit at YNH and started attending meetings. At some point, I joined as part of the group as a listener, started helping with the Gala, became a board member and eventually became the liaison of PATH for Norwalk Hospital. Because pre-maturity is something near and dear in my heart, I wanted to find a way to make a difference in parents lives with some kind of light shining at the end of the road. That became PATH for me.

I do not have any one memorable event with parents and PATH, as every person has different needs at different points of their stay in a NICU. Although I have mentioned PATH to many people here at this NICU, there seems to be more of a connection as a listener with a parent. I have become very close with many of the parents here and love to find out that there was a connection made with PATH that helped make a difference. Having walked the walk, and talked the talk with countless parents trying to make sense of pre-maturity and all it entails, I have found that no two people have the same needs. However, I have also found that misery and hope love company and that many parents find solace in the fact that we all initially start out miserably sad, but still go on hoping to get the chance to love our children and live in their futures.

**By Cathy Abbot**

**NICU Nurse, Norwalk Hospital.**

### **You've Come A Long Way Baby**

Ariana Sofia Balayan was our first live birth after two pregnancy losses. Unfortunately, even with a cerclage, my cervix opened and Ariana was born just shy of 25 weeks gestation at Yale on 1-13-84. She weighed 720 grams (1 lb 9 oz) and went down to 1 lb 6 oz at her lowest weight. She was 12 inches long. The doctors gave us little hope for her survival, and even less hope that if she did, she would not have long-term effects. She was on a respirator for 9 1/2 weeks, had a grade 2 bleed, as well as a host of other complications. She came home on 4-11-84, on theophyllin as well as an apnea monitor, after 3 months in the hospital. She was on the monitor for almost a year. At about 3 years old, she was finally caught up developmentally and size wise to toddlers her age. She is now almost 22 years old, a senior in college, and a gift to us. She has always done phenomenally well in school. It is a miracle and we enjoy every minute with her. She is a theatre and dramatic literature major and has accomplished much on the stage as well as behind the scenes. She has traveled extensively and studied abroad. Her career goal is to be a stage director and have her own theatre company. Her zest for life never fails to amaze us and we feel incredibly lucky to have had this gift of our daughter...a true miracle. We still feel so indebted to the Yale NBSCU and the amazing people there.

In 1987, Ariana got a little sister from Korea...Lorien Kim Balayan...and then our family was complete. Adoption was a wonderful way to complete our family and so much

easier than infertility, pregnancy loss and 3 months in newborn intensive care! We highly recommend it!!!

We were founding members of the PATH group, as we wanted to provide support to parents going through similar experiences as ours. Little did we know how it would take off!! We are so proud to have been a part of PATH and congratulate them on their 20th anniversary!

Sandy and John Balayan

### **Ariana's Story**

I understand the events surrounding my birth are quite miraculous; in fact family and friends often refer to me as "the miracle baby". However, it is not until I think about it in depth that I truly realize the magnitude of it all. I was born at 25 weeks gestation instead of 40, weighed 1 lb. 9 oz. and was 12 inches long-all because my mom's cervix did not work properly. Obviously, I do not remember it, but I do know that in 1984, doctors did not give me much chance of surviving. I had very little chance of being "normal" Physically and mentally if I was to survive, but I am as "normal" as anyone else my age. I doubt I would have survived if I were not fortunate to be taken care of the incredible doctors at Yale New Haven Hospital. I was on a respirator and in intensive care for 3 months, in which my parents stayed by my side, and talked and sang to me. I do not believe I would have survived if they had not decided to love me regardless of whether I would live or not. I am so lucky to have had the love and support from my mom and dad, and they continue to support me in any endeavor I take on. I think about the circumstances surrounding my birth from time to time, especially as I prepare to graduate from college. The largest thing I take from the experience is I think I survived for a reason. I do my best to live life to the fullest and take advantage of every opportunity I am given. I am about to graduate from Wheaton College in Norton, MA with a BA in Theatre and Dramatic Literature, concentrating in Directing. I have always had a passion for the stage; I started by acting and singing in musicals through high school. My ultimate goal is to run my own theater company, and direct there. I just directed my first full-length play at Wheaton, *Les Liaisons Dangereuses*, to much acclaim. At Wheaton, I have been involved in many clubs and activities, including the Wheaton Chorale and Wheaton Chamber Singers, Tour Guide in the Office of Admission, Co-Chair of the Relay for Life, and I am currently President of my all female a capella group, the Whims. We have a tradition where every senior chooses a "senior song" which they arrange and then solo on. I picked "Wonder" by Natalie Merchant, for its appropriate lyrics in relation to my birth. Last year I studied abroad all year, at the intensive Eugene O'Neill Theater Center in New London, CT in the fall and London, England in the spring. This past summer, I worked at Barrington Stage Company in the Berkshires of MA, and really connected with the people and environment. I am returning there to assist the Artistic Director in January, and next summer. To parents who are struggling with a preemie infant in the NICU right now, I would say do not hesitate to name your child, and love them for everything they are. I can imagine it is a difficult time in your lives-but there is hope. I am living proof.

**Ariana Balayan**

## **PATH Kids**

**By Kiki Thorington**

**Age 10**

**5th Grade**

**St Thomas the Apostle School**

I love Stephe as if she is my sister and whenever she gets sick and has surgery, I always pray for her and tell my teacher and the whole class prays for her. Like sister's we get on each other's nerves but eventually we fix the problem. Before Stephe was born, I thought people with medical problems or disabilities could not do anything but since I know Stephe I have learned that people who have medical issues can succeed in life even though it is at their pace. When other people make fun of people with medical issues, I always stand up for them, knowing it is not their fault but the way they were born. I am thankful that I have my cousin Stephe because I would not know anything about people with medical issues or disabilities. Now I know that they have feelings just like me for example they are nice, they get sad or mad just like anybody else. I believe that everyone should know someone with a disability and treat him or her like a human being.

## **PATH on the Move**

**By Carmina Cirioli and Nanfi Lubogo**

**Co-Executive Directors**

There is an African saying that states, "In order to know where you are going, you have to be able to see where you have come from." As PATH celebrates its 20th Anniversary, one cannot help but reflect back to where it all began.

PATH was founded by a group of mothers who sought support from each other while tending to their sick children at the NICU in Yale New Haven Hospital. Each of these mothers was dedicated to help support other families and lessen the isolation that they often felt when their newborns were in the hospital. They did this even while they cared for their own children and the up and downs and tragedies that came along with that. Over the years, it has blossomed from a small support group for mostly premature babies to a network recognized and utilized by many across CT. Today PATH has an active network of over four thousand (4000) people made up of supporters and families with a pool of about two hundred (200) Listeners. PATH is what it is today because of these courageous women and the legacy of their children.

### **Looking Back at 2005**

In the summer, PATH hosted the Third Annual Fun Day, a family outing, at a Bridgeport Bluefish baseball game. This year we will expand that event to include the New Haven Cutters and the New Britain Rock Cats. Look for updates on the website. The summer also saw the completion and launching of our new website: [www.pathct.org](http://www.pathct.org). We encourage you to continue to visit and welcome your comments. Exciting additions are on the way such a message board and chat room. **\*\*\*PATH is looking for an individual with experience in moderating message boards who is willing to volunteer their time. Interested parties please call: 1-800-399-7284 or email: PATHP2PCT@pathct.org.**

In the fall, PATH completed the mini grant from the CT DD Council. We created a promotional video, for use as an outreach tool to mostly under-represented communities. PATH wishes to thank the DD Council for funding our request. Also in the fall, PATH had the opportunity to network with many key disability organizations and parents of children with special needs at an award and recognition banquet hosted by the Milford Mayors Committee for People with Disabilities. The networking opportunity was priceless and PATH is enthusiastic to forge new relationships and help more families as we continue to grow.

### **Looking Ahead in 2006**

One of our major focuses this year will be to re-establish relationships with our hospital partners as well as form new ones. We will begin by coming back full circle to where it all began, Yale New Haven Hospital. At a recent meeting with key hospital staff, many exciting ideas were discussed and PATH was invited to collaborate with the hospital in making them a reality. Some of these ideas will include projects such as the refurbishing of the family waiting room in the newborn unit, named for PATH many years ago, as well as several onsite events for families, such as a support group and fun family activities. Stay tuned! PATH has already begun coordinating meetings with many other CT hospitals and will keep you informed on the progress.

The PATH event to attend this year will be our 20th Anniversary Celebration- PATH's 13th Annual Gala and Silent Auction event. We hope that you, our biggest supporters, new and old, will join us to mark this very important event in PATH's history. "Save the Date" cards have already gone out so be sure to mark your calendars. New this year, is the option to utilize our website to purchase your tickets through a secure PayPal service. For more information, please visit [www.pathct.org](http://www.pathct.org) & look under News and Events.

In closing, we cannot forget to thank our Founders and all that had a hand in making PATH what it is today, as well as each and every PATH family for all your support over the last 20 years. We are often overwhelmed by the response and support that many families turn around and reciprocate to PATH. You have shared many touching stories and miracles with us for which we are grateful. Truly, without you, there would be no PATH. Thank you, thank you!

## **THANK YOU'S**

Over the past 20 years, PATH has enjoyed wonderful relationships with many hospitals across CT. This is usually the first introduction to the medical/disability world and roller coaster ride families find themselves on when their children are diagnosed with a medical condition. Even if it does not seem like enough, PATH and the many families that we serve would like to pay tribute and say THANK YOU to the many doctors, nurses, social workers and hospital staff who have taken care of our children. Through out the year, we will continue to feature heartfelt letters from PATH families to our professional partners. Here a few below:

### **Dear Jennifer Pappa and Anne White.**

I know I have thanked you many times before for the care you gave to Kevin (and our whole family) during the weeks after his birth. We were, and continue to be, so thankful for your kindness and knowledge back then and have not forgotten you for a moment. The most important thing you gave to us was the confidence to care for our own child and to learn from him instead of feeling inadequate when we did not have all of the answers. We continue to be amazed by Kevin as he grows, learns, and loves life. We are forever grateful for your role in that! Thank you, thank you, thank you!!! We love you.

### **The Lynch Family**

**Carolyn, Tom, TJ and Kevin  
Westport, CT**

### **Dear NICU staff at Norwalk Hospital,**

Our family is forever grateful to you for the compassion and care that you showed us during the three months that our son, Addison, was there. His stay there was such an intense experience with emotional lows and incredible highs. The doctors and nurses became like family to us. It would be too difficult to single out just one or two individuals that impressed us the most because so many people played critical roles in working towards the eventual outcome...bringing home a happy, healthy baby. Our family thanks you.

**Meredith and Adam Siburn and son Addison (age 2)**

### **Dear Dr Law:**

It has already been 3 years since you left us, yet you are still very much in our hearts. Thank you for the loving care that you showed us, never faltering, never thinking about yourself, always about your patients, even towards the end. You were a true angel, living amongst us. Even though you are sorely missed, we are grateful for the times we had. Stephe is almost 7 yrs old and doing well and has a little sister, Emily. Somehow, I think you know that, we know you watch over all your kids. Your friends and the staff at CCMC carry on your legacy through the Nancy's Kids Foundation and you remain in the hearts of all the families whose lives you continue to touch.

**We miss you, we love you.**

### **The Lubogo's**

**Nanfi, Steven, Aaron, Stephe and Emily**

**Dear Dr. DiMario:**

You have known Christian all his life - from the days he lived in the NICU at birth - to the present, when we come to our visits at CCMC for a neurological check-up. We have been so very grateful for all your help and support through out the past twelve years. It is a pleasure to come for a visit, as you are always smiling and make us feel like welcome guests. You have the best bedside manner of any doctor we've ever worked with and we know that Chris is in the best of care in your hands. Thanks for being there for Chris and all the other children you take care of. You are truly a great doctor.

**Susan Rosano & Christian Grimaldi**