

# ARPKD Chapter

PKD Foundation | Fall 2010

## A Message From Your Coordinators

It's hard to believe that summer is here and it's time for the PKD Convention and the 2010 Walk for PKD. It feels like yesterday that we were in Chicago at the last Convention and talking about the 2009 Walk. We learned so much last year in Chicago and know this year will be equally informative. Read below to find out the exciting news on the 2009 walk and how much money ARPKD families raised! We are hopeful that this year's walk will be as successful. We also look forward to seeing familiar faces and meeting new friends in San Diego.

If you did not receive the recent Progress Magazine please email us so we can add you to the mailing list. The entire issue was about ARPKD and we were very excited with all of the information provided.

If you would like a specific link to be added to our next newsletter and/or you would like to be our "feature family" tell us! And, as always, if there is anything we can do for you, please let us know.

Julia Roberts (404-731-8931) & Michele Karl (914-522-6193)

Co-coordinators  
arpkdchapter@pkdcure.org

*Michele is still handling the newsletter, so if you have any inclusions or questions for Q&A, please let her know: michelehopekarl@gmail.com.*

## PKD CONVENTION INFORMATION

The 2010 National Convention on PKD will take place from Friday, August 6 – Sunday, August 8 2010, at the Sheraton San Diego Hotel & Marina San Diego, CA. There will be a separate ARPKD track for all ARPKD families. The sessions will include an introduction to ARPKD, CHF (congenital hepatic fibrosis), dialysis and transplantation, the emotional aspects of dealing with ARPKD, nutrition for ARPKD, a parent to parent roundtable, and new this year will be sessions on grieving and loss. There will also be a pizza party and our informal yearly chapter meeting as well as an ARPKD hospitality suite.

### **Is attending the PKD Convention a financial hardship?**

Scholarships for a caregiver in an ARPKD family are being offered for families that find it difficult to attend the PKD Convention because of the financial hardships that can and often do hit with a diagnosis of ARPKD and the on-going treatment of a chronic disease. A special anonymous donation, designated for caregiver scholarships for National Convention attendance has been established. Depending on need, the National Convention registration, travel and hotel may be covered.


Please contact Tara Fitzgerald at taraf@pkdfoundation.org or 800-PKD-CURE for a simple application!

We hope to see you there.

## Chapter Coordinators

Julia Roberts

Michele Karl

 [www.pkdcure.org/arpkdchapter](http://www.pkdcure.org/arpkdchapter)

 [arpkdchapter@pkdcure.org](mailto:arpkdchapter@pkdcure.org)

 Julia: 404-731-8931

Michele: 914-522-6193

# LINKS

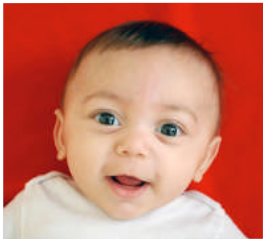
## **Social networking site for parents of children with special needs:**

<http://supportforspecialneeds.com/> - Taken from the introduction on their site about "special needs": It's an all encompassing label, yet we let a diagnosis divide us among this powerful group of advocates and caregivers into categories of rare and not-so-rare diseases, genetic conditions, developmental delays and the unexplained afflictions. We have more in common than separates us and Support for Special Needs is the community that offers a chance to exchange wisdom and ideas among one of the most powerful group of people we know. Join us as we learn from each other about how to help our kids and ourselves.

**The leading nonprofit organization for pregnancy and baby health:** [www.marchofdimes.com](http://www.marchofdimes.com) - dedicated to improving the health of babies by preventing birth defects, premature birth and infant mortality.

**Blog written by a mother of a four year with ARPKD who had a successful liver and kidney transplant almost two years ago:** [www.caringbridge.org/visit/andrewmorrisey](http://www.caringbridge.org/visit/andrewmorrisey)

## FEATURE FAMILY – THE DUNN FAMILY



When my husband and I found out we were pregnant we knew that Henry would be special because he was our first child but we had no idea just how special. When I was 37 weeks pregnant I went in for a routine ultrasound and there we found out that Henry's kidneys were measuring 6 cm each and that I had no amniotic fluid. After the ultrasound our doctor told us we had to go to the hospital right away and that we would deliver our son that day. I remember the nurse at the hospital saying that the ultrasounds can be wrong and most likely everything would be fine. When I started having contractions Henry's heart rate dropped. It was then that I knew everything wasn't ok and I had an emergency c-section.

When Henry was born his apgar scores were 9 and I remember the joy I felt when I heard him scream. On the way to the nursery though things took a drastic turn for the worse and Henry's lungs collapsed. He was taken by ambulance to the Boston Children's Hospital, which had a level 5 NICU. It was there we learned that Henry had underdeveloped lungs and two pneumothoraces as well as failing kidneys. I will never forget when the NICU doctors sat us down and explained that they were taking things minute by minute and they weren't sure if he was going to make it.

Henry did make it though. Everyday he took small steps to getting better. He went from being on a ventilator to leaving the hospital breathing on his own. He went from having failing kidneys to having fully functioning kidneys. We don't know why or how but for some reason Henry pulled through and continues to thrive. Like many children with ARPKD Henry's disease still needs to be managed. He is on medication for high blood pressure and we are frequently at the doctor's office checking his blood pressure and having labs done to make sure his kidney levels are normal.

When Henry was in the NICU my husband and I started a blog for him to keep our family updated. To this day I still take pictures of Henry, make videos and post updates often. I think it's important to tell Henry's story because when I first found out Henry had ARPKD I felt so hopeless. Many other ARPKD blogs helped me out when I needed someone to relate to. The ARPKD community has been amazing and given me the hope, support and information I need.

Today when people see Henry they can't believe where he started and how well he is doing. Most days I can't either. He looks and acts just like a normal 6 month old. I feel privileged to have Henry as my son and try to cherish every day I have with him. I will never forget what it felt like to look at his little body connected to so many machines and how hard everyone prayed for him to pull through. He truly is our miracle baby.

## WALK FOR PKD

In the 2009 Walk for PKD there were 68 ARPKD teams who raised over \$215,000. Of those teams there were 6 visionaries (individuals who raised over \$6,000) and 7 team first teams (teams that raised over \$10,000). This year the PKD Foundation started giving out a new award to the walk with the most ARPKD teams and to the ARPKD team that raised the most money.

The 2010 Walk for PKD will take place mostly in September and October of this year. Again there will be a chance to have your team listed as an "ARPKD team". Go to [pkdcure.org](http://pkdcure.org) to register to walk.

# REMEMBRANCE

This section is in honor of those babies who have lost their lives to ARPKD. If you would like your child's name mentioned here in future newsletters please email us to let us know.

## Remembrance

Remembrance is a golden chain

Death tries to break,

but all in vain.

To have, to love, and then to part

Is the greatest sorrow of one's heart.

The years may wipe out many things

But some they wipe out never.

Like memories of those happy times

When we were all together.

~ Author Unknown

Zachary DiMarzo May 3-May 4, 1998

Audrey Raquel Oest February 18-February 19, 2000

Helen Grace Marks May 24-May 26, 2002

Alexis Taylor Hall June 16-June 30, 2002

Carley Devin Grove October 22-October 23, 2002

Noah Samuel DeRycke September 16, 2003

Emma Theresa Spies July 10, 2002 -October 23, 2003

Noah Raynham Lyons December 29, 2004

Ava Helena Wallheimer January 14, 2003- November 5, 2005

Aidan Shaw VanderCruyssen October 2-December 3, 2005

Kylie Miracle O'Gorman Dec. 20 -Dec. 21, 2005

Cameron Alexandra Glynn May 25-June 1, 2006

Ryan Michael Ortiz February 27-March 4, 2008

Cole Thomas Smith March 18-March 19, 2008

Mia Elizabeth Zaccone August 19-August 20, 2008

Juniper Isabelle Wakely December 10, 2008

Elena Catherine Rodriguez October 15, 2007-January 7, 2009

Brooke Madeline Krittman January 9, 2009

Trevor Rhys Seidel March 9-March 23, 2009

Bowen Lee Urban March 26-March 29, 2009

Jody Michael Terian April 10th 2009

Van Fredrick Weisshaar May 7- May 8, 2009

Ashlynn Jean Parkhill May 2-May 4, 2009

Bridget Katherine McCaffrey January 29, 2008-June 7, 2009

Addyson Laraine Humphries July 4-August 30, 2009

Nicholas Matthew Fleming August 11-September 9, 2009

Theo Joseph Berry December 31, 2009

Lindee Beau Urban March 18, 2010

Zoe Gellin Brown May 30, 2010-June 2, 2010

Nolen Bradford Chandler June 25, 2010 – July 1, 2010

# KIDNEY WISE

Brilliant Eats by Kelly L Welsh, R.D., C.D. is an easy to follow cookbook that was written by a renal dietitian, who is also a kidney disease patient. There are nutritious and simple meals that the entire family can enjoy. To purchase Brilliant Eats you can go to [www.pkdcure.org](http://www.pkdcure.org) or to [www.kidneywise.org](http://www.kidneywise.org).

## Here is a sample recipe from Brilliant Eats:

Yucatan Lime Soup

Prep Time: 30 Minutes

Servings: 4

Ingredients:

2 corn tortillas, cut into strips

vegetable oil spray

1 tbspn olive oil

½ cup onion, finely chopped

8 cloves garlic, minced

2 serrano chili peppers, thinly sliced

1 medium tomato, halved crosswise and seeded with skin removed

4 cups no salt added chicken broth

1 ½ cups cooked chicken breast, shredded

1 bay leaf

¼ cup lime juice

¼ cup fresh cilantro, chopped

ground black pepper to taste

Preheat oven to 400 degrees. Arrange the tortilla strips on a baking sheet. Spray with vegetable oil spray. Bake for 3 minutes or until lightly toasted. Remove from oven and place onto a plate to cool. Heat oil in a large saucepan over medium heat. Add onion, garlic, and chili peppers. Cook until the onion is translucent. Add tomato, broth, chicken, and bay leaf. Simmer for 8 to 10 minutes. Add lime juice and cilantro. Season with black pepper. Taste and add more lime juice if desired. Serve with tortilla strips sprinkled on top.