



# Preemie Family

## Preemie Life

### *Claire Josephine & Mary Gladys Sharkey*



Photo Credit: Sharkey Family

**Gestational Age at Birth:**  
23 weeks, 5 days

**Weight at Birth:**  
Claire: 1lb. 2oz.  
Mary: 1lb. 4oz.

**Days in the NICU:**  
Claire: 103  
Mary: 14 days (angel wings)

**Proudest Moment (NICU):**  
Mary: the first time we held Claire after Mary passed away; Christmas Eve morning when Claire went from vent to CPAP; Claire taking a bottle for the first time ever!

*Coming Soon:*

Check [www.PreemieWorld.com](http://www.PreemieWorld.com) to learn more about Claire and Mary's journeys.

### **Parent Tip:**

*Take it  
"one day at a time."*

## Advocate: Feeding Tube Awareness Week

Many preemies have a feeding tube during the NICU stay as they work toward eating orally. And many also go home on feeding tubes. **February 7-13, 2016 is Feeding Tube Awareness Week** brought to you by the **Feeding Tube Awareness Foundation**. Learn more, and get great resources and inspiration by going to their website at: <http://www.feedingtubeawarenessweek.org>

## Preemie Resource: Preemie Therapists Move the World

PreemieWorld provides a number of free handouts to be used in the **NICU and beyond** in its "Freebies For You" section of the website. **This month's freebie is "Preemie Therapists Move the World."** "The OTs, PTs, NT's, Speech/Feeding, Music, and Vision Therapists are amazing," comments Deb Discenza, co-Founder of PreemieWorld, LLC. "Whether in the

hospital setting or out in the community, they are key to helping families with those developmental milestones." Parents and professionals alike will appreciate this freebie in that it is easy to print and reproduce. **So go download it here now:** <http://preemie.us/PreemieTherapists> And check out many more here: <http://bit.ly/PreemieFreebies>

## To Do List



**CONGRATS: Courtney Balliro** won *Helping Your Child with Extreme Picky Eating* by Katja, Rowell, M.D. and **Peter Schnellenger** won a copy of the *little man* DVD.



**LIKED US YET?:** PreemieWorld is doing another PreemieWorld Facebook page contest. See page 2 of this newsletter for details!



**Download PreemieWorld's FREE tools** <http://bit.ly/PreemieFreebies> to use and to pass onto others.



**MARK YOUR CALENDAR!**

*The Champagne Ball*  
Toby's Shower for Babies  
February 12, 2016  
Denver, Colorado, USA  
[www.ShowerforBabies.org](http://www.ShowerforBabies.org)

*7<sup>th</sup> Annual Project Cameron Bookraiser*  
Project: Cameron's Story  
February 19, 2016  
Queensbury, New York, USA  
<http://preemie.us/ProjectCam>

*Have an event you want to share with our community? Contact us at:* [connect@preemieworld.com](mailto:connect@preemieworld.com)

*Tools and Resources  
for the Preemie Community*

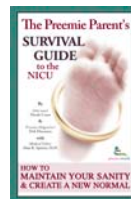
## Term: Developmental Delay

**Developmental Delay:** Babies are expected to reach certain milestones (i.e. walking and talking) within a predictable amount of time. Premies, due to their early birth and subsequent medical challenges, may take longer to reach those milestones. Many Premies receive occupational therapy (OT) and/or physical therapy (PT) to deal with all of the various issues



of being born too early; the stress it puts on the muscles, the stiffness in the bodies of infants that are on the vent for any length of time, etc. This therapy is very important for your baby. If your baby is vented, ask your nurse to get an OT/PT consultation. Some infants receive therapy early on after discharge, others do not require it and the parents can take a "wait and see" approach. Your pediatrician can guide you through this and may refer you to your area's Early Intervention program.

*This excerpt is from  
The Premie Parent's Guide  
to Survival in the NICU on  
sale at [www.PremieWorld.com](http://www.PremieWorld.com)  
\*\*We do bulk orders for  
hospitals\*\*  
[connect@preemieworld.com](mailto:connect@preemieworld.com)*



## Support: Parent to Parent NICU Family Support

*Six months after having a preemie, **Becky Hatfield** was asked to start her NICU's support group. To date, they have supported over 20,000 families.*

**Established:** 1975

**Outreach:** Regional through the University of Utah Hospital via Utah, Idaho, Nevada & Wyoming.

**Facebook:** <http://preemie.us/P2PofUT>

**Instagram:** [parent2parent\\_ut\\_nbicu](https://www.instagram.com/parent2parent_ut_nbicu)  
(password: weheartpreemies)

**Programs:** Support meetings in the form of Pizza Night, Craft Night or Bingo Night, a catered dinner each month, "Survivor Beads" program and two events, a reunion and an annual dinner with an award. Also provides hospitalized/bed rest support and a NICU baby shower.

Parent to Parent  
UNIVERSITY OF UTAH  
HEALTH CARE

## PreemieWorld: "Like" Us On Facebook & You Could Win!



Visit PremieWorld's FB page at:  
<http://bit.ly/FBPreemie>

**"Like" our FB page  
from 1/26/16 to 2/22/16 and you  
could win a copy of the award-  
winning *little man* DVD from  
PremieWorld!**

<http://bit.ly/FBPreemie>

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today @ [www.PremieWorld.com](http://www.PremieWorld.com)



### The Details:

**By:**  
Cheryl Campbell along with various artists

**Available at:**  
[www.musicforpreemies.ca](http://www.musicforpreemies.ca)  
[iTunes](#)

**Cost:**  
\$9.99 (iTunes) - \$15.00 (site)



## Once, in a Lullaby is a Premie Classic

The research is clear on music in the NICU: it is brain food. It provides a soothing backdrop for preemies but it also stimulates them in terms of breathing, feeding and more, which quickly translates to earlier discharge. Cheryl Campbell, a classically trained soprano, music teacher and preemie mother crowd-funded a CD that could be donated to families in the Mount Sinai NICU. With 16 soothing classical pieces mixed with pieces of a lullaby quality (like "Over the Rainbow"), Campbell has done a superb job. Grandparents, families, and friends will find this a perfect gift for preemies in the NICU.

*We're giving away this CD! Follow us on Twitter by 2/22/16 to enter: <http://bit.ly/PremieTweets>*

## After the NICU: Finding A Good Therapist

*Whether its Early Intervention or private therapy, finding a great pro is important!*

- **Early Intervention:** Talk to your Early Intervention Coordinator and ask about whom would be the best fit for your child. Not happy? Call again and request a switch. It is that easy.
- **Private Therapy:** Referrals are often the best. This could be from a local support group that you have joined; a local special-needs organization or the specialist referring your child for therapy.
- **Note:** Always check insurance coverage, and make sure to get and follow-up on references.

***Tweet Us:** What's your #premietherapy suggestion?*

## Premie Support Online

### On the Premie Support Forum on INSPIRE:

Connect with *over 24,000 parents of preemies online for free* at [www.Inspire.com/preemie](http://www.Inspire.com/preemie) for the **Premie Support forum**. It is the largest and most active forum online, *moderated by our own Deb Discenza*.

Feeding Associated Apnea or Bradycardia - *In the NICU/PICU*

So Many Questions . . . - *Introduce Your Very Important Premie*

Full Term Baby After Premie ☺ - *Introduce Your Very Important Premie*

- Potty Training My Micro-Premie - *At Home (Years 1-5)*

### On PremieWorld's Twitter Page:

PREEMIE UPDATE: Audrey

### On PremieWorld's Facebook Page:

GREAT INFO: When the Common Cold Turns Serious: How to Recognize RSV

### On PremieWorld's LinkedIN Group:

STUDY: Infant Delivery & Feeding Methods Can Affect Gut Composition

Combination of ROP Treatments Might Help Eliminate 'Destructive' Laser Therapy

25 Words I Learned After Having a Premature Baby

## Get "Social" With Us!



[www.PremieWorld.com](http://www.PremieWorld.com)  
[www.LittleMantheMovie.com](http://www.LittleMantheMovie.com)



@PremieWorld



- PremieWorld
- Premie Parent's Survival Guide to the NICU



PremieWorld



Check out other LinkedIN groups we moderate:

- NICU Professionals
- Early Intervention Professionals
- Premie Parent Support Group Leaders
- Premie Parents

*Tools and Resources for the Premie Community*



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## Preemie Parent Words: *When Premie Therapy is "Stuck"*

**Deb Discenza** *gives insight into realizing when it is time for a change-up in the therapy regimen.*

My daughter was 10 years old and the local therapy center near her elementary school had only a Monday at 8 a.m. slot for us, so we took it. At first she did well and we saw some progress. However within a few months, my daughter was half-asleep, grumpy, annoyed and downright ornery during those sessions. And the therapy homework wasn't getting done either because I was getting pushback from my daughter.

It was then that I realized we were "stuck" in therapy and needed a break. We pulled out and gave my

daughter some breathing room. But I was deathly afraid of her regressing on the gains in balance and coordination and I was constantly trying to find ways to help make exercise fun.

Fast forward a year and I finally decided that it was time for something that combined therapy with fitness and hired a personal trainer at the local gym. The trainer had the background we needed. My request - keep it fun, keep it moving. He has done just that. My daughter loves her training sessions and is aware of how it is helping her in school and in life. *Success!!*

*How have you gotten "unstuck" in #premietherapy?*