

About here4U & This Site



Our Story

In December 1999, my life was forever changed with the birth and death of my infant niece, Riley Ann Dooley. Born with a malignant brain tumor, which went undiagnosed, Riley graced our lives for two weeks during Christmas and then left us, and this world, on January 2, 2000. During this time, I reached out to a dear friend who had lost a son, Dylan, also at two weeks of age, for an “instant education” about what to do when you have a baby “born dying”. I asked what would be important for my sister and her young family to do while Riley lived, and as (more?) importantly, about what she *didn't* get to do with and for Dylan, that she wished she had. Her sage wisdom and counsel was invaluable and I believe our experience with losing Riley was better because we'd learned from someone who had walked a similar path before us.



The power of sharing these stories and experiences with others when going through a medical journey with a child, no matter how big or small, young or old the child is, was not lost on me. It became the impetus for co-founding Compassionate Passages, a non-profit which was all about advocating, educating and conducting research to support dying children and their families.

While Compassionate Passages was making much progress in its mission to be the voice for better supportive care for dying children and their families, I had to leave the organization as I was experiencing my own caregiving struggles and losses, providing hands-on care for my own seriously-ill and dying family members-- my Sister, Mom, Dad, Mother and Father-in-Law, and Brother-in law. Each of these illnesses and deaths brought me more lessons and closer to what it was like to be in this world of caring for a loved one who is chronically-ill, seriously-ill, or dying, and I knew I had to do something more with all of this.

In 2013, I formed a new non-profit, called here4U. here4U gets me back to YOU, the families and children, I so long to listen to, be here for, and just help navigate and support on your own complex medical journeys with your child or children. I know how hard it is to do this kind of hands-on care for those we love, while managing everyone, and everything else, that still has to be taken care of—a house, other children, a spouse, work, sports, homework, grocery shopping, paying bills...the list goes on.

While here4U started with the vision of building a pediatric transitional care/hospice/respite house for our seriously/chronically-ill kids, and their families, in Southeast Michigan (which we're also working on), it has expanded. We now also want to provide a 24/7 online resource for families like yours...a “safe place” for education, idea exchange, and intimate conversations

with other families of children facing complex medical paths so that you're not so alone on this journey.

It is my hope that you will find the support you need here when questions, issues, and challenges on this medical journey with your child arise. You are not alone. We are here for you and journey with you as we work to become a caring and compassionate, yet comprehensive website, that embraces, educates, and empowers you, your child, and the entire family, at every step of the way.

With all my love and support,

Ann Fitzsimons

Ann Fitzsimons

Executive Director and Founder of here4U, Inc. & Riley Ann's Aunt

Our Mission

here4U, Inc. is a collaborative partnership of parents and healthcare professionals which has been established to support families of chronically or seriously-ill babies and children from the time of diagnosis throughout the rest of the child's life. We know that the parental concerns about what is best for your chronically or seriously-ill child, or child who has a complex medical condition, are not always addressed. So we've made it our mission to embrace, educate, and empower you, your child, your family on this medical journey through the provision of a variety of supportive care resources.

Our Initiatives for Supporting You & Your Family

here4U is focused on three key projects to better help and support families like yours; however, we're relatively new, so these are all still in the early stages of development. Please keep checking back as we update our supportive care offerings and resources for you.

Our main initiatives include:

- (1) Creating this online website (and eventually, a web-based online community as part of this) as a "safe place" for education, idea exchange, and intimate conversations among and with families on complex medical paths with their child;
- (2) Conducting research to give voice to kids with medically complex/serious health conditions, and their families, by understanding what they need, want, and desire to be better supported inside and outside of the healthcare system; and
- (3) Creating an actual, physical "home" where these children can come in Southeast Michigan for transitional care, as a bridge from the hospital to home; for respite care when family issues/emergencies arise; and for hospice and end-of-life care, if and when needed.

However, we are ALWAYS open to hearing from you about thoughts, ideas, questions, things you'd like to see addressed or built in as part of this website, so please feel free to contact us at either info@here4U.net or through the Contact Us page on this website. We want this to be YOUR site, so please help us build it to be what YOU want and need it to be. Thanks!

Our Guiding Principles

We believe that...

- Families and children living with chronic, complex, or serious medical conditions/illnesses are entitled to education about their disease, information about the risks and benefits of treatment, and what the likely outcomes will be.
 - We will strive to help equip you with the skills needed to find and/or ask for the information you need to make educated care choices for and/or with your child.
- Families and children living with these serious or chronically-disabling conditions should be encouraged, and are entitled, to be involved as partners with the care team, in shared decision-making with their child's healthcare team and other medical professionals, and in planning treatments for their child.
 - We will share what other families have told us has been helpful to them in becoming partners with their child's medical team so that you, and your child, can find ways to have a voice in this process.
- The extended family suffers, as well as the child, when a serious illness or a chronic disorder strikes families. Pediatric patients, and their extended families, are entitled to compassionate and expert medical care, effective control of pain and physical complaints, and emotional and spiritual support.
 - We will identify resources within and outside the healthcare system, which will help you advocate for this kind of care and access to these services for your child and the rest of the family.
- Experience has taught us that children should know what is happening to them. The child's voice, whenever and wherever possible, should be included into this decision-making process. Even very young children should have some involvement in discussions about what is happening to them. The sick child has a right to have a voice and to be heard in helping make decisions about his/her own healthcare.
 - Part of the support we will offer will be directed at helping you to learn ways to have and encourage open communication with your child, to advocate for your child to have a voice in his/her care plan discussions/decisions, and to empower your child to speak up for him or herself, when willing and able.
- And, importantly, we want to help "add life to your child's years, not simply years to your child's life" (per the American Academy of Pediatrics' Committee on Bioethics).

A Message to Parents & Families/Friends of Chronically/ Seriously-Ill Children

"Hope lies not in a way out, but in a way through"

Robert Frost

Dear Parents, Family Members, and Friends of Chronically/Seriously-Ill Children—

You've likely gotten to this website because you're worried, confused, frustrated, or scared for your child's health and well-being. Your child may be chronically or seriously ill, or have been diagnosed with a complex medical condition, and you're unsure where to turn. You have lots of questions and not a lot of answers. You may be feeling alone and very overwhelmed with all that you may be facing. We're here to help you.

This website has been developed with the questions and needs of families of children with medical conditions or illnesses like your child's in mind. In fact, some of the creators of this site have children with these conditions, have lost a child through such illnesses, or have provided support to family members who've had or lost a child through illness or accident. What we're trying to say is, we know what it's like to be in your shoes and we want to help walk this journey with you as you plan out where to go and what to do from here...for you, for your child, for the rest of your family.

We've talked to and listened to lots of families with seriously ill children. We've heard what kinds of questions they've had and what's been helpful...and sometimes, not so helpful, in situations like these. As a result, this website is being developed around what we've learned from other families like yours. So please feel free to use as much or as little of what's offered here to help you, to help your child, or to help a family or friend with a child who is seriously or chronically-ill. And if you can't find the information or supportive help you're looking for on one of these web pages, please feel free to contact us. You do not have to do this alone.

Your supportive care partners in this journey,

The here4U Family

About this Site

This site was developed by and for families of children with chronic or serious illness or complex medical conditions, and by those who care for them. It's meant to help you ask yourself the important questions about what YOU want for your child's care AND what your child wants. It's also designed to help provide some guidance on key questions or issues you may be facing at this point in your child's illness. Feel free to use this site in whatever way works for you and also to take advantage of the other resources it links to for further information.

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