



## Welcome!

If you are reading this, then you, like all of the contributors to this booklet, love someone with juvenile idiopathic arthritis (“JIA”). This booklet has been created by parents who are ‘Empowered by Kids’, as a reminder that we are not alone.

Each letter or story in this booklet is written by a person with JIA or their parents. While each letter comes from an individual with their own experiences, beliefs, opinions and backgrounds, all share a common thread – we are not alone.

Some of us are fairly new to the world of JIA – a world that is filled with new symptoms, medications, tests, doctor’s appointments and a whole new vocabulary. Others have been on this journey for quite some time.

We each bring a personal and unique story to the table, but we all share a common need to hear the words “me too”.

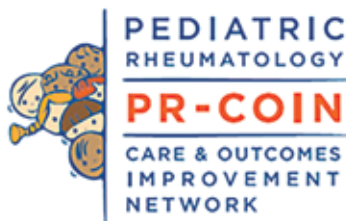
As parents, we all understand how important it is to see our kids feeling well and living a normal life, in spite of JIA. Yet we can easily become consumed with worry about our child’s diagnosis and feel trapped without the ability to help.

PR-COIN (Pediatric Rheumatology Care and Outcomes Improvement Network) is a network of teams at rheumatology centers working together to transform how to deliver care to children with JIA. PR-COIN offers parents an exciting opportunity to get involved as part of the care team, to share our unique insights and collaborate to improve care and health for children with JIA. Parents are involved locally with their care centers and nationally within PR-COIN. Together we are improving the rates of children in remission! We encourage you to work together with your care team collaboratively. You know your child best and are an expert in his or her care, your voice can be a powerful advocacy tool, and by working together we can accomplish great things. We are all in this together, and together we will make life the very best it can be for our JIA kids and the JIA kids of the future. Together we are going to make a difference for everyone living with JIA.

Best wishes to you and your family

The Parent Working Group of PR-COIN

You are invited to visit <https://pr-coin.org/> to track the progress the network is making. If you are interested to roll up your sleeves and get involved as part of the team, contact the PR-COIN parent working group on Facebook at [www.facebook.com/groups/prcoinparents/](http://www.facebook.com/groups/prcoinparents/) or email [prcoinparents@gmail.com](mailto:prcoinparents@gmail.com)



When trying to put into words how I feel about my child's diagnosis of juvenile arthritis the one word that comes to mind over and over again is hope. We have hope that there may be a cure soon. We have hope that she will have a productive life with this diagnosis. We have hope that the doctors know the right course of treatment for her. And most of all we have hope in her future being bright. When Mariah was diagnosed in 2011 at the age of 5 with a type of arthritis called polyarticular spondyloarthritis our world was shaken. As parents we have expectations for our children to conquer the world. And this diagnosis isn't in those expectations. Watching your child incapacitated isn't in those plans. Watching your child live in a body that is attacking itself isn't part of that plan. Finding out your child has inflammation in almost every joint in their body isn't part of the plan. But there is hope. I will never forget the moment I felt undeniable hope. We were sitting in a room of over 1200 kids at the first Juvenile Arthritis Conference we attended, and a man got up to speak and said, "If we were sitting here 30 years ago with all these kids, they would probably all be in wheelchairs!" As he said that I looked through the room and saw less than a handful of kids in wheelchairs. My heart almost leaped out of my chest. As horrible as this disease is there is still hope. There is a whole community of 300,000 kids that needs to know there is hope. These warriors are stronger than we can imagine. They just need to know with hope anything is possible. Mariah said during an interview with one of our local newspapers, "Just because I have this disease doesn't mean I can't be a kid. It may be really hard someday, but I'm not scared!" And with her superstar sister, Mauriauna, by her side she never is scared!

Tory, Mauriauna & Mariah

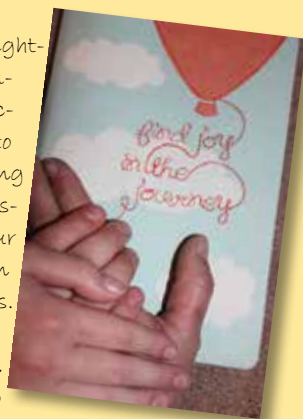


Hearing the new diagnosis, Juvenile Arthritis, can be frightening. What does it mean when your child has arthritis? Immediately, thoughts of grandparent's arthritic hands go racing through your mind. Somewhat relieved to get answers to what's been happening to your child. As you get farther along the journey, you'll have more of an understanding of the disease. As a parent, you have a huge responsibility in how your child will cope and choose to live with their disease. Just when you think you understand it, the pattern of disease changes.

It's crucial that you choose, JOY! There is always something to be thankful for, whether it's new treatment options, caring physicians, or connecting with new friends who also have juvenile arthritis, or the news that your child is in remission. As a parent with Juvenile Arthritis since three years old and having two children with systemic Juvenile Arthritis; I encourage you to stay calm and choose JOY! Your child picks up on your stress, how you handle treatment and their daily pain and illness, as well as flare ups.

Your child needs you to be strong and trust that they are going to be A-OK. Allow them to be a child, play like others and pursue their dreams. Don't allow Juvenile Arthritis to steal your JOY!

FIND JOY in the JOURNEY!  
Heidi, mother to Jake and Hannah



Megan was diagnosed with Poly JIA at the age of 21 months. We realized something was wrong when she was 18 months old, not walking, and strongly disliking physical therapy aimed at helping her walk. Babies are chubby, so I never even noticed the swelling in her wrists, knees, ankles, fingers, and toes. When we were first diagnosed, I wish someone had told me "There are families all over the world sharing your same struggles. Here is a list of online and in-person support groups so you can talk to another parent who shares your story." It took me almost a year to find such a thing on my own, and I hope no parent has to go through this alone.

The parents and patients I have had the pleasure of "meeting" though online groups have been amazing. They all understand the journey, although no one has the exact same experiences. The differences we have among our members allows a very well-rounded list of opinions, suggestions, and advice whenever a question arises. This diverse feedback truly allows a parent to make the most informed decisions in partnership with their doctors. Living with JIA is truly like riding a rollercoaster, with highs when you feel hopeful to lows when things are going every way but right. Thankfully, we are in a hopeful place right now, but I vividly remember the lows, and don't wish for anyone to do it alone.

Melanie, mom to Megan



I've had to search for the **"Beauty in the ashes"**.

I expected to see friends suddenly disappear. To lose my family because they couldn't give us the support we needed. I expected my daughter's life to be one challenge after another. I expected to work hard with the school, therapists and doctors. I expected the anger, depression and isolation. But it's things that I did not

expect that throw me still today.

I didn't expect to witness small miracles everyday as I watch Raegan accomplish another goal. I didn't expect to become the advocate that I have become for all kids and parents who need a little help along the way. I didn't expect the courage I was to gain in waking up each day to face a new challenge. I didn't expect my daughter to grow into this funny, intelligent, beautiful girl that speaks with her smile, without saying a word.

I didn't expect the friendships I would come to treasure, with people who never would have entered my life under normal circumstances. I didn't expect to come to love all kids with special needs, to look past the disabilities to see only sweet, determined souls. I didn't expect to want so much more for them; more services, more respect, more fun.

I didn't expect that one of the worst days would turn into many wonderful and fulfilling days.

There is not a day that goes by that I am not angry that it had to be my child. But I was able to turn that anger into something positive.

Looking back I can see the "Beauty in the Ashes". You see, I've gained more from this illness than it has ever taken from me.

Kari, mom to Raegan



When Chris was officially diagnosed at age 11, I felt an immense sense of relief. I know when your child is sick, that is not the one emotion most people think they should feel. You see, our family had just endured 8 months of bouncing from doctor to doctor, diagnosis to diagnosis. All in the elusive search to

find out why my once active little boy's knee was the size of a cantaloupe. I remember sitting in that rheumatologists office and hearing the words Juvenile Arthritis. Thinking our lives would never be the same. Would he ever walk right again? Can he continue his Scouting? Will he be in a wheelchair? All those things were going through my mind, but the overwhelming sense of relief came with those words. Relief that we finally knew what we were fighting. We now had a game plan. Someone knew what was going on with our sweet boy. We know knew what we were fighting. Flash forward five years and I have a very active 17 year old. Chris in the past year was awarded his Eagle. He is active with his local AfJROTC wing and walks the neighborhood 3 times a day with his dog. He knows he has to monitor his activity and his joints. He knows what he can do and has learned an amazing skill at figuring out a way to achieve his goals by different means. I have watched him grow into an amazingly compassionate young man. JA doesn't have to define a person, but we as a family have decided to define it.

Sarah, mom to Chris



**“At age 7, I was a very active child. I loved to act, dance, swim, and do karate. When I first started feeling pain, I went to a foot doctor to see what was the matter with my left ankle (my most swollen joint). I ended up getting a cast which is the worst thing for arthritis. When the cast came off, I was 8 years old and the pain did not subside. My mom, with help from my pediatrician, decided to take me to a pediatric rheumatologist, who then told me I had Polyarticular Juvenile Idiopathic Arthritis. Since then I have been on many different types of medication, including shots, infusions, and hospital visits. Now, at age 13, my infusions have helped many of my joints and I am still able to move almost as good as the average kid. Even though there is definitely sometimes pain, the achievements I have made with arthritis are big and they have made me proud. Just remember: No matter what arthritis makes you feel like, just keep going because the possibilities are endless.”**

**- Kylie, age 13**



I was diagnosed with juvenile arthritis when I was 12, just a few days before Christmas. Since then, my life has been a tornado of flares, pain, and medications. But that's not all it's been; it's been hope, too. I met other kids who had arthritis when I was 15, and it was the most amazing feeling in the world. There were others just like me! They understood exactly what I was feeling and going through! They had helpful tips and I was even able to give them some advice. I hadn't know any other kids with arthritis before. Sure, I knew they had to exist, because my pediatric rheumatologist was always swamped with patients, but I'd never met them.

There is hope. There is always hope, no matter how bad things look. We're fighters, and fighters always come out on top, because we learn from every experience.

When I was first diagnosed with JA, I was nearly eaten away by my loneliness. Don't. You, reading this, are now part of a family that is 300,000 strong; you have 299,999 brothers and sisters who understand you completely. We will never let you go through anything alone; we will always be there.

Laura, age 18

## After the Snowball Hits

"Is this like asthma?" I asked. My husband knew what I meant. He used to be terrified every time I wheezed and would race to bring me an inhaler while I laughed at his comical expression of fear. I've had asthma my whole life and thankfully it's usually no big deal. It was new to him though and it scared him badly. Here we were now, waiting for the elevator at Boston Children's Hospital, our youngest, just a little toddler, newly diagnosed with Juvenile Arthritis.



Asthma was the only lifelong illness I could compare it to. I was hoping with all of my heart and soul that this was like my version of asthma, just an annoying part of life.

Having my child diagnosed with such a serious, unfamiliar chronic illness was like stepping off of the sidewalk and finding nothing but air underneath me. Somehow I was still standing, still walking but it was completely nonsensical. It took time to process. It took fear and worry and grief for the loss of the imagined life

she would lead. And as time passed our new normal created itself. There were doctors and therapy and testing and medicines, but there was also school and friends and beach days and holidays. My child was growing everyday with this disease and every day she was living her life.



Katherine is ten now and amazing. She loves school and piano. She's artistic and smart. Her friends greet her with hugs and teachers remark on her kindness.

Katherine's arthritis is challenging. It seems smarter than us most of the time. Unfortunately for Katherine JIA is a very big, life altering deal. It is also just a part of her life, a part that is helping her grow up empathetic, caring, and remarkably strong.

Raising a child with Juvenile Arthritis is challenging. It can be scary and isolating and sad. The disease loves to keep you on your toes, throwing new problems at you as soon as you control the current ones. It steals time and energy and so many moments of childhood. Reach out. Support is there. Ask your rheumatologist, connect through Facebook, call the Arthritis Foundation. Ask questions, research, read. Know that life has just hit you with a big icy snowball and is watching and waiting to see what you do in return. Love your child, listen to her, listen to her care team and then take her and go play.

By Kirsten, mom to Katherine



I remember when we finally gotten the diagnosis of Juvenile Idiopathic Arthritis, it was such a relief. We finally had an answer of what was going on with our youngest child. I never questioned why, because having the diagnosis of JIA explained so much. Fast forward a few years, by this time our 4th child had been diagnosed with JIA, (yes, we were that family with 4 kids with JIA), I started really questioning what we had done wrong as their parents. How could we really have given 4 of our children these really crappy genes? It is a very



dark place to go to. But here is the thing, yes my children have this disease and our lives are very different than the average family from daily medication, weekly shots, to monthly infusions X 4 children. Added to this, the multiple doctor visits each week and daily trying to cope with having 4 kids with a chronic disease, stiffness, pain, not being able to move, walk, write, participate in life like a normal child can make a person just want to scream. To put it mildly, it can be soul sucking.

In life you get to choose your actions. We can dwell on the negative and to focus on what we have lost, or we can choose to focus on the positive and what we have. The positive list is endless of what we have gained from having 4 children with JIA. Our family is much closer because of this disease. We are kinder and gentler to each other now. We live in the present moment, living each day to the fullest. We choose to be active in the JIA community. We have made lifelong friends both locally and nationally. We get to travel and be amongst people who get what we are going through. If I cry, they understand my tears, if I am stumped with a daily living problem because of JIA, 9 times out of 10 one of our JIA friends has a solution. There is always someone to share our triumphs and victories with this disease and when the days get too much to handle, there is always someone to wipe our tears. Reach out to the JIA community, surround yourself with support, ask questions, listen and learn. You will get through this. I am not promising that it will be easy, but it will be life changing in ways you could never imagine and one day you will smile and then before you know it, you will be laughing again with your child.

Heidi mom to Liam, Levi, James & Maggie





Hello new family.

I'm sorry that we are becoming acquainted in this way but please know that you are not alone. We understand what you are feeling. Our son Maddox was diagnosed at 17 months with severe polyarticular JA and uveitis. You may be feeling relieved that you finally have a diagnosis after so many initial doctors visits.

Or you may be feeling confused about why this is happening to your child, or angry, or guilty, or worried for the future, or sad, helpless, scared, alone, resentful... we get it. We've felt all of those before and continue to occasionally rotate through those feelings... but we are also ok now. We feel grateful, happy for the good days, proud at different developmental stages and milestones, impressed with the incredible amount of empathy and emotional intelligence our children seem to have with a chronic illness. This disease is hard- it's full of ups and downs and the moment you get to a good place and start to let your guard down you inevitably seem to hit a roadblock. It's ok though. These hardships are defining your child's character and your child will become stronger and wiser. You will get through this...and when you think you can't - pick this book up or talk to another parent in a support group. You've made it through every rough day up to today successfully. You've got to keep moving ahead. Trust your intuition if something doesn't seem right and be your child's advocate. Most importantly, reach out to someone that understands when you need help. You and your child will be ok!

-Jorge and Krissie (parents) and Maddox (4yo) with little brother Paolo





My name is Grant, and I was diagnosed with Juvenile Arthritis when I was only two. Still, I considered myself lucky. My case was mild, and I had almost 9 years of remission before the disease resurfaced with a vengeance. Late in my 4th grade year, I started having ankle pain. At first, everyone thought it was "just" growing pains. By the time I was in 5th grade, it was hard to walk. After a long wait, I was able to see a rheumatologist again, but the treatments weren't controlling my disease. By the time I was 12, my arthritis was out of control. I had been hospitalized several times, and my

internal organs were even affected. The next few years were very hard. I couldn't even go to school! I felt like I lived at the doctor's office. It was hard to be a normal kid. I had to be involved in hospital homebound and homeschool programs as well as give up sports for a while, but I didn't let it stop me. I never gave up. I got stronger again by working hard in physical therapy and having patience to find the right treatment plan. I used my experiences to fight back against JA. I became an Arthritis Ambassador and spoke on Capitol Hill. I served as the youth honoree for Chicago's Walk to Cure Arthritis. I raised funds and awareness so that other kids might have a better chance to fight this disease. Today I am 16 and able to do all the things I love again. I am back in remission, and I am able to be a dual sport athlete at one of the top ranked high schools in the nation, and it looks like I have a good chance to go on to college athletics! No one who meets me now can believe all the things I have been through, but I just say I am the perfect example of how things can turn around with great doctors, hard work, and a positive attitude.

Grant, age 16

Mom, Kim





There are people out there that think their biggest problem is they got a bad grade, or someone didn't invite them to a birthday party. Some kids even make jokes because they don't understand how hard it is to deal with a disease like this.

I was diagnosed with polyarticular juvenile idiopathic arthritis at age 11, but had pain since I was 5. Just because I don't look sick, doesn't mean that I'm not sick. They always make fun of me because I have to miss school so much. It's so easy to judge someone on what they are wearing or how they look, you need to walk a mile in their shoes before judging them.

For example, I consider myself lucky I have juvenile Arthritis and let me tell you it absolutely sucks, there are times I feel bad for myself but I need to remember that always there will be a better day ahead. A saying people always say is to "look at the bright side" and when I thought about it how could there possibly be a bright side to this? To tell you the truth after thinking about it, I can say because of Arthritis: I am stronger. Before I had arthritis I thought differently, I guess you could say I had a different perspective. I'm not saying that I'm always looking at the bright side of things, but I'm trying. I know I am strong, and I have learned to understand myself better. When you are facing something hard, it's ok to be sad or angry, but think there is always someone who has it worse.

In the movie *Soul Surfer* which was based on a real story, Bethany Hamilton loses her entire arm in a shark attack yet she kept surfing, don't let a bump in the road control your life. As Bethany Hamilton said "I don't need easy, I just need possible". Don't give up, be brave and face what's coming. I believe I have the power to fight this disease!

Valentina, age 13  
Mom Marcela



There are so many thoughts and feelings a parent experiences when their child is diagnosed with a chronic disease. You may feel overwhelmed with information and prescriptions and questions about what the future holds for your child and for your family. That's how I felt when our family began this journey more than fifteen years ago. And that's what it is to me---a journey. At first, it seemed like a journey at sea where the waves really battered our boat, and I was having some trouble getting my "sea legs," trying to be strong and calm and gather information, yet sometimes feeling like the "sea" might be getting the best of me. These days, I've gotten my "sea legs." You will, too! There are still storms along the way, when the unexpected happens.

Sometimes this journey seems more like a trip across the country, with hills and valleys and an occasional steep mountain. Sometimes the road seems smooth and you're motoring along, and at other times you're hitting a lot of bumps and ruts along the way.

Some tips from for navigating this journey: stay grounded. For me and my family, we hang on to our faith in God. Also, know that people have traveled this journey before you, and more people will be starting on a similar journey. You can get support, insight, and friendship from the former; you can support and encourage the latter:

Tammy (parent of a 17-year-old Anna, diagnosed at 23 months)



Being a mother of two amazing boys is the greatest gift in my life. Both of our sons have juvenile arthritis. My husband and I strive to live a life of love and believe anything is possible with **HOPE**.

When our youngest son was diagnosed with systemic on-set juvenile arthritis, we were relieved. After over a year-and-a-half of searching for a diagnosis and hearing he could have lymphoma or another form of cancer, we finally had an explanation for his daily severe fevers, rashes, and pain. Little did we know our journey would continue to frighten us, while also teaching us more than we could ever imagine.

Over the next four years, our youngest endured many procedures and treatments leading up to our oldest son's diagnosis. He has a milder form, spondyloarthropathy. And although we knew much about JA, we were now searching for the best treatment for our oldest son.

Dealing with chronic illness is a very difficult journey. People always ask us how we do it...for us, we power ourselves with prayer, knowledge, and research; and we trust in our children's doctors. We also believe in our gut instincts and ask questions. We try to keep balance in our lives because the medical situations can be stressful and overwhelming. However, the complexity we have dealt with has led us to amazing joy: we love deeper; we appreciate our family and friends with all our heart; we find wonder in everyday miracles; and we are grateful for the kindness shared with us.

Having two children with JA is a journey. As you and your children grow on this journey, may you always find HOPE to carry you through and give you strength.

Rochelle, mother to Logan and Parker



Two years ago, I was also diagnosed with a mild form of arthritis known as spondyloarthropathy, which is essentially permanent tendonitis. Though I have a mild form of arthritis, I have personally experienced the brutality of the disease by witnessing what my younger brother goes through on a daily basis. I've seen my younger brother suffer in ways that I can't even imagine, and it is extremely hard to watch at times, but I stay positive. Since my brother's diagnosis, we have attended multiple national juvenile arthritis conferences, and have made lifelong friends at them. The families that my family has connected with over the past years have shown us that we are not alone; they gave us hope, and have supported us when we were at our lowest of lows. Once my brother was diagnosed in 2010, I knew that I wanted to go into pediatric rheumatology. There is currently no cure for juvenile arthritis, or arthritis in general, but I hope to change that one day; I want to put a stop to the suffering that the 300,000 children in the United States, who have arthritis, endure on a daily basis and I am more determined than ever to find a cure. In the meantime, we have to stay hopeful. We have to stay hopeful as patients, parents, siblings, and friends. We have to stay hopeful that there will be a cure, and that these children will, one day, be pain free.

Logan





Deora was diagnosed with Juvenile Arthritis when she was only 20 months old, but she had symptoms before that. She began limping, and even though she was an early walker, she would cry to be carried up and down steps. At the time, the only joints that were affected were her knees, so her rheumatologist gave her injections in both of her knees. That seemed to work wonderfully, until she started getting pain and swelling in both of her ankles.

She began taking weekly shots of methotrexate which work very well for her. She has been off of the methotrexate twice after doing very well; however, the arthritis always manages to find a way back into her poor little body.

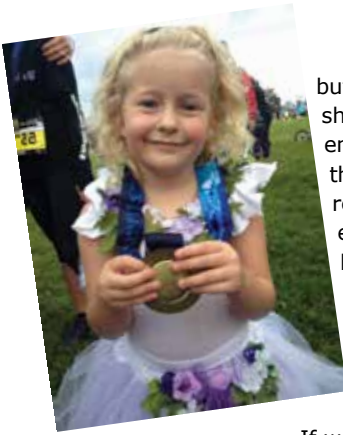
I remember getting a phone call from the preschool when she was four. I was stuck at work and had to call her pappy to pick her up because it hurt too much for her to stand up at circle time. I remember panicking during the H1N1 virus knowing that kids with weakened immune systems were dying (hers was weakened due to methotrexate). I remember her having a bad reaction to the naproxen she was prescribed (it caused her to cry and say she didn't deserve to be loved - she was four - and yes, the doctor agreed that it was the medication causing depression). However, I feel that those days are gone. We have had ups and downs and I always thought that arthritis would take the center stage of our lives, but it doesn't anymore. My daughter, like many others, wouldn't let it.



She is now seven. She dances and plays soccer very well. I wonder if she even remembers that little girl who couldn't wake up and jump right out of bed. There is no more hiding when it is time for shots. There is no more panic when I send my child out into the world to go to school everyday. Even though she is on immunosuppressant drugs, I get sick more than she does. While we are not sure of what the future has in store, I know that my Deora is strong, and maybe one day I, as her mother, will get there myself.

Debra, Mom to Deora





I know it might be difficult to believe right now, but everything will be okay. We've walked in your shoes and we know full well the rollercoaster of emotions you are feeling. While the gravity of hearing this news may weigh heavily on you at this time, rest assured it will eventually fade and make way for everything else in life – school, play dates, sports, bumps and bruises.

Jessica is a warrior, full of life, energy, curiosity, confidence, determination, spunk, and beauty. She was diagnosed with JIA at just 20 months old and is now 5, leading the active lifestyle of a child.

If we can offer any words of encouragement, it would be to believe in your child, love them and empower them to live life to their fullest potential!

Do not let Juvenile Arthritis define your child. A blood test might tell you about an illness, but it certainly cannot measure one's resiliency, strength, courage, humility, compassion, and beauty. Your child is more than a test!

You and your child are not alone. There are people just like yourselves willing to offer support, you just have to look. While your family and friends may not know the depth of what you are feeling, don't be afraid to let them in. Your team of doctors who know how to treat this disease can also provide a wealth of support and guidance.



Believe! Believe in yourself! Believe in your child! Believe in your medical team! There will be good days and bad days. There will be days when simply getting out of bed is a challenge or when frustration will go into overload as everyday tasks take that much longer to do. We promise you though; there will be many good days too. Days filled with proud smiles as your child accomplishes something they have worked so hard to achieve and days where they will be pain free doing the things they didn't think were possible days prior. Everyone experiences struggles in their life. There will be times when your child cannot do something, but believe and don't ever lose hope that one day it will be possible!

Your child may have Juvenile Arthritis, but Juvenile Arthritis doesn't have them. Never underestimate your child's abilities and the power they have to make a difference!

Kristen, Mom to Jessica Age: 5





“You are in so much pain all the time because you have Juvenile Arthritis.” Those words validated everything. I wasn’t just being a wimp, it wasn’t all in my head; my immune system was to blame! I was 6.5 the first time they suggested that Juvenile Arthritis was the cause behind my always aching body but it was not until I was 14 that the reality of the

diagnosis hit me. Growing up with an incurable autoimmune disease can be incredibly isolating. One day I decided that if I was going to have to live with this disease than I needed to know more about it. So I found an online support group filled mostly with parents of children with JA. I learned more about my disease, about things that helped and things that could make it worse. I chose to become empowered by what I did have control of rather than a victim of the thing I couldn’t control. I made it my goal in life to not just learn to live with it, but to live despite it. Having JA is not fun but you do not have to give up your dreams! I went to college, learned how to run, started a career, got married, and even became a mom. You are the author of your life story and while this diagnosis was never part of your plan just know you can still live a good life despite it. You are brave, strong, and so amazing.

Lisa



Hannah was diagnosed with Oligoarticular JIA ANA+ at age 4. I had certainly never heard of THAT before! The diagnosis brought a lot of answers to questions that had not been answered for most of her life. Probably the first thing I felt after her diagnosis was relief. Learning about this disease was very scary. I knew adults who had different kinds of arthritis, but kids can get arthritis too? Not the same as adults. This is very different. After the initial relief, fear and anger set in.



There is a lot to take in and absorb. SO MUCH to learn. After a year, I understand more than I ever thought I could. As a parent, you will be stronger than you think and you will be faced with emotions you never knew you would feel. But it's ok. Grieving after this diagnosis is normal. I wish I understood that sooner.

An early coping strategy was to just read and read... anything I could get my hands on. I felt like I was learning a lot, but felt so alone because I didn't know anyone else who was dealing with it. Besides the doctors and nurses, who could I talk to? I had so many questions. Then I found online support groups and resources.

I wasn't alone anymore. Educating myself about the diagnosis, scary drugs and treatments, and the terrifying effects of this disease, turned to reading post after post of parents and older kids with JIA that shared stories, hopes, dreams, fears, experiences, suggestions, honesty, support, happy good days and tear jerking cries of hatred for this disease.

You will grieve. You will cry. You will find people to share that with and moments to celebrate. Hannah is doing really well right now. She can run, jump, dance, swim, and go to pre-school. She can be a five year old little girl! There are a lot of things that go into keeping it that way because of JIA. Some days are still better than others, but she never ceases to amaze me. We are faced with an unknown future, but we are certainly celebrating how she is doing right now! Your child is strong. You are strong. You are here for a reason.

Jennifer, Mom to Hannah



I still remember the first time I knew something wasn't right with Calvin's legs. He was a walker around 18 months old. He fell a lot!!! One day he sat crying. You know the cry, the "I'm hurt" cry. Finally, after about 5 years of Dr. visits, he was diagnosed with Oligoarthritis.

Anyone that knows Calvin knows he is a ball of energy. To look at him play, to watch him play soccer, or perform gymnastics one is just shocked when they hear his diagnosis. I am so amazed at his courage and bravery. I don't think he fully grasps what immense strength he shows us. Calvin is wise beyond his years. His dream is to one day be an Olympic gymnast. Although he doesn't mention it as much anymore, my dream is that one day soon, there will be a cure which would make both of our dreams come true.

We have made the decision as Team Calvinator to participate in research studies, fundraising efforts and well, pretty anything that will help bring an end to this disease. Calvin has made the commitment at the young age of 7 to make sure no other children have to go through what he is going through.

Remember one thing, you are not alone. Your child is not alone. You have a vast legion of support. We are all here to help your journey through this thing called JIA.

Sarah, Mom to Calvin



I was diagnosed with juvenile arthritis when I was 12, just a few days before Christmas. Since then, my life has been a tornado of flares, pain, and medications. But that's not all it's been; it's been hope, too. I met other kids who had arthritis when I was 15, and it was the most amazing feeling in the world. There were others just like me! They understood exactly what I was feeling and going through! They had helpful tips and I was even able to give them some advice. I hadn't know any other kids with arthritis before. Sure, I knew they had to exist, because my pediatric rheumatologist was always swamped with patients, but I'd never met them.

There is hope. There is always hope, no matter how bad things look. We're fighters, and fighters always come out on top, because we learn from every experience.

When I was first diagnosed with JA, I was nearly eaten away by my loneliness. Don't. You, reading this, are now part of a family that is 300,000 strong; you have 299,999 brothers and sisters who understand you completely. We will never let you go through anything alone; we will always be there.

Laura, age 18



Becca was diagnosed with polyarticular JIA at 13 months of age. She has arthritis in both wrists, one of her fingers, her knee and neck. She went from a very active child to barely being able to crawl. About 2 years after her diagnosis, Becca was also diagnosed with Uveitis. Becca is treated weekly with methotrexate injections and she also receives Remicade infusions ever two months. She is such a brave little girl. Each week she faces her shot with no fear.

Our family has attended several events with the Arthritis Foundation so our family can learn more about arthritis from other families, and for Becca to feel that she is not alone. We were able to attend our first Juvenile Arthritis Conference in Colorado. This was a life-changing event. As a parent, I was able to meet many specialists in the fields of Rheumatology and Uveitis. I was able to come back home with the knowledge that in the last 50 years, the treatments for kids with JIA have improved exponentially. Children like Becca are in less pain, and are suffering so much less than children diagnosed years ago with this disease. I attended round table discussions with doctors and other parents. The parents were able to share stories, and be there to laugh and cry together. Becca was able to meet other children and adults that have arthritis like her. It combined learning and fun to make the children's experience unforgettable.

Becca and I both made friendships from around the country that will probably last forever. We met people from all over the country. It was such a wonderful shared experience. It was like a family we never knew we had.

Nikki, Mom to Becca



Gianna was diagnosed with Juvenile Idiopathic Arthritis when she was 15 months old. I began giving my daughter injections of methotrexate which helped to alleviate some of her symptoms but after a couple of months, the rheumatologist decided to add a biologic drug to the mix: Enbrel. She responded very well and within a short time, her limping had disappeared and she was walking nearly perfectly again. We did do some physical therapy but eventually just signed her up for toddler gymnastics which was super helpful for her. It not only gave her a chance to socialize with other kids but it also got her to use her body in ways she wouldn't do at home or even in physical therapy.



Gianna loves to dance and any time she hears Justin Timberlake she has to "shake her booty". Our kids have to endure a lot, as do we, but they can lead "normal" lives and have "normal" activities. We just have to teach them to listen to their bodies and know their physical limits. The most important thing you can do to help your child through this journey, is to take care of yourself. The single most important piece of advice I would offer you, is to reach out and find another JA parent you can talk to. There will be days when you just need a shoulder. And there will be days when YOU will be someone else's shoulder. It will help you, and that will help your child.

Tina, Mom to Gianna

Alyssa was diagnosed at age 6 with juvenile idiopathic arthritis. When she could no longer walk up and down stairs, bend or run was when reality set in there was something wrong. We also found out she has a clotting disorder so her treatment would be a difficult one. Alyssa has to be hospitalized every time she needs to get her joints injected. She is not a big fan of hospitals as any kid would feel.



This disease is like a roller coaster. We learned that as a family, and with the support of other's, we are able to make this journey in life a positive one. We try to keep involved in every aspect we can from volunteering to selling candy and t-shirts to raise money to educating the public. We hope for a cure.

We push Alyssa to achieve and believe she can do whatever she wants if she puts her mind to it. She loves dance, but had to stop because it was too much so we enrolled her in karate and she loves it. She even won her first beauty pageant this year. We will not let this disease consume us. Her strength, determination and the will to fight makes her the true warrior she is. It is the key that will allow her to succeed in life. Always teach them to never give up! They have to be fighters and give it their all, and know we as parents will always stand beside them. They are our HEROES!

People need to know that kids get arthritis too. They are normal kids and deserve a fair chance at anything they do.

Donna, Mom to Alyssa



When we were given the diagnosis of juvenile arthritis, it seemed as if all control was stripped from our hands. What would we do now? What would the future look like for Cameron (then 8 years old)? We had two choices, suck it up and do what had to be done, or sit back and let this disease rob our family of everything we held dear. Of course, we sucked it up and moved on. Joint injections under



anesthesia, MRI's, medications which were hard on his little body, did have a marked impact on our lives, but we tried to do as much as we could to keep life normal. Soon, I found connections with other people who are living the same lives we were through camps, Arthritis Foundation events and support groups on facebook.

As his disease was getting in control, Cameron and I got involved in advocacy. Using my voice to positively impact the life of not only my child, but EVERY child with JA helps regain control, piece by piece. Cameron and I have been to Washington, DC four times to advocate for all 300,000 children in the US with JA. Cameron has now began to advocate for himself. He knows he has a voice and that voice is powerful.

Cameron is 5 years out from his diagnosis. He has been off medications, in remission for over two years. In spite of having arthritis, he has become even more than the kid I always thought he would be. His experiences with JA have instilled in him a sense of empathy I would not have expected. He is an amazing young man and I am proud to be his mom.

Angela, Mom to Cameron age 13



**Never underestimate  
your child's abilities and  
the power they have to  
make a difference!**



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