



# Inspirational Patient Award

## Parker Lentini

Parker Lentini is an incredibly strong and resilient 16 year old who has systemic-onset juvenile arthritis with overlap syndrome including: myositis, psoriatic features, vasculitis, Raynaud's, ankylosing spondylitis, and hypogammaglobulinemia. While he has literally fought for his life these past eight years, he has never given up hope for himself and all the other children with juvenile arthritis. ([www.purpleplayapower.blogspot.com](http://www.purpleplayapower.blogspot.com)). Parker believes "you're never fully dressed without a smile" and "with hope anything is possible".

Since diagnosis of JA 6 years ago, Parker has fought hard while also raising over \$105,000 towards a cure and to support families impacted by JA. Parker is an Arthritis Foundation's Ambassador and the 2016 National Walk to Cure Arthritis Youth Honoree, was the 2013 local Tampa Walk Honoree, and has served on the AF's 2015 Juvenile Arthritis Conference committee. In addition, he was the 2012 Parrot Heads of Central Florida's Fruitcakes in the Alley Child Honoree, recipient of Make-a-Wish, a 2012 St. Joseph's Hospital Kids Are Heroes Awardee, co-founder of a small two-year non-profit (High-5-Club) raising gas/food money for families whose children are in treatment, the 2015 Bruce Rossmeier Ride for Children Gala's keynote speaker to benefit Serious Fun Camp Boggy Creek, and a speaker at various advocacy events and fundraisers. He has contributed towards research by participating in the RAPPOR study. Most recently, Parker will be recognized this fall with the PhRma "Visibility in Progress" award. Parker and his family also continually raise awareness through their family blog: Parker's Purple Playa Power Pounding at JA .

### **Parker says:**

"So, life with Juvenile Arthritis (JA) is pretty hard, as you might suspect. But I try not to let that stand in the way of me doing the things I love. Before I was diagnosed with JA, I was a very athletic kid and my favorite thing to do was play sports. Now that I have JA, I am no longer able to play sports, but I try not to let that hold me back. I decided to find new things that bring me joy and don't flare my arthritis. Now, I enjoy such things as playing video games, photography, videography, watching movies, collecting super hero stuff and hanging out with friends. And I utilize some of my talents to advocate in my community. For instance, I have made several videos explaining my life with JA to advocate and bring awareness to this disease.

One of the most difficult things I've had to do during my JA journey is find a medicine that works for me. This disease has been very aggressive. In late 2013, I participated in a study that both saved and changed my life. To start the study they had me do something called a washout period. During that washout period they stopped almost all my medications including my IVIG which is blood plasma. This was pretty hard, but little did I know how much worse it would get. When you start out on the study, you either get the real medication or placebo, which is basically nothing. But after a month into the study everybody ends up getting the real thing. Of course, we were hoping I'd get the med and all would be good. Unfortunately, I got placebo. We knew I got placebo right away because I continued to get progressively worse. As I went into the second week things started becoming dangerous. My pain went through the roof and I ended up going into macrophage activation syndrome (MAS). It was at this time my doctor came into my hospital room and said that I could stop the study right then and there. And without a second thought I said NO! Prompting her and my mom both to ask why. I said that it doesn't matter what I feel right here and now. What matters is that by going through with this study, I could help kids with arthritis in the future. And that's when my mom looked at me gave me a hug and starting crying. Together, as a family, we made it through that study and I stayed on that medication for almost 3 years. And that's the longest a medication has ever kept helping me.

This is the main inspiration for doing all the things I do. I do it for all the kids with JA in the future and present. I just hate that any kid has to go through what I'm going through. And if I can do anything to put a smile on those kids' faces, you bet I'll do it. Until there is a cure, I will continue to contribute towards research, advocate loud and proud, raise awareness with my voice and experiences, and fundraise to help families in the here and now and for the future cure. But my favorite thing to do is to share a smile and a few kind words with children who fight this disease with such strength."

Thank you for all you do, Parker.

You truly are an inspiration!

The International Foundation for Autoimmune Arthritis & World Autoimmune Arthritis Day Committee

*Patient Inspiration Award*



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