Voices of Parents Carry HOPE

Panel: Angela Miney, Bobby Sloan, Danielle Tipton, & Dan Wenger
Moderator: Rochelle Lentini
Angela

- Charlie, Angela, Helen and Catherine
- Catherine has SJIA
- Diagnosed: February 2002 (when she was 6), now is 20 years old
Angela

• Use of many biologics, steroids, anti inflammmatories over the years; still using them even though she has not flared in a long time

• Words of wisdom: “Keep her fit and keep her moving”
  – gave us (her family) something to take control of when we didn’t seem to have any control over anything that was happening to her
  – had to learn to trust a healthcare team and a healthcare system that we had no knowledge of.
Angela

• A good relationship with your healthcare team really helps.
  – If you turn up when things are going well, they will be there for you when things are going badly.

• Camp had the biggest impact on Catherine and now she’s even become a camp counselor.
Bobby

- Heidi (wife), Jake (son), Hannah (daughter)
- Both children have JA, both have SJIA (Systemic Juvenile Idiopathic Arthritis)
  - Some may recall this being called “Still’s disease”
Bobby

• Hannah & Jake
  – Hannah diagnosed at 2 ½ years old, now 11
  – Jake diagnosed at 7 years old, now 13
  – They also both have Polyarticular JIA features & Ankylosing spondylitis

• My wife, Heidi
  – Also grew up with JIA, and continues to battle the disease today.
  – Heidi diagnosed at 3 years old, and now...well men shouldn’t share their wife’s age

#Yes4Hope
Bobby

• **Children’s Treatment**
  – NSAIDs, Ibuprofen, Naproxen, etc.
  – Started on DMARDs, Methotrexate, along with folic acid, anti-nausea meds & Celebrex
  – Next step: Biologics - been on several biologics & have been on two biologics at the same time
  – Along with the biologics came steroids
  – Steroidal joint injections to knees wrists and jaws
  – Splints on wrists, hands, and knees.
  – Physical, occupational, and aquatic therapy & body massages
  – Counseling sessions during difficult time in their journey

#Yes4Hope
Bobby

• Words of Wisdom:
  – We feel it is very important to educate yourself to the best of your ability; you are your children’s best advocate. If you don’t know, you can’t advocate as effectively as you could. Most importantly never give up hope and keep moving, our motto is “use it or lose it”

#Yes4Hope
Bobby’s Family High Light

• A change in life style
  – We moved to a little farm in Tennessee. This change has made a great difference in our children’s life. The farm lifestyle has created a more active environment which has benefited them greatly.
Danielle

- Kevin, Ashley, Emily and Zachary
- Emily has Mixed Connective Tissue Disease (MCTD) & Dermatomyositis (JDM)
  - Diagnosed at 5 yrs, now 13
- Zachary has psoriatic arthritis
  - Diagnosed at 8 yrs, now 12
Danielle

• Emily started on Methotrexate & Naproxen; Enbrel added and well maintained about 2 years. Thought she was in remission.
  – Symptoms changed, condition worsened, which led us to very high doses of steroids and Remicade. We thought Remicade wasn't working well, so Ocrenia and Actemra were both tried, and failed. She is currently maintained well on Remicade, Rituxan and CellCept.

• Zachary had a good three years on Enbrel and Methotrexate. We just recently switched him to Remicade.

#Yes4Hope
Danielle

• Biggest celebration was our Make A Wish trip.
  – It was one of the most difficult years of our lives, and having something amazing to look forward to and make memories with helped immensely. We still talk about our trip, and use it to inspire us and give us hope.

• Words of Wisdom: Try to roll with the changes and never expect things to stay as they are.
  – Every time we've had a new diagnosis, hospitalization, or some other trauma, we've had some enormous blessings following. We look at the little things that are good every day. It can get you down if you don't try to keep a positive attitude.

#Yes4Hope
Danielle

• Research, research, research...

• Empower yourself with knowledge so you can help your child as much as possible.
Dan

- Angie (spouse), Nick (16), Emma (14)
- Emma has Ankylosing Spondylitis, Enthesitis and Uveitis
  - Diagnosed at 4 years old, now 14 years old
Dan

• Current: 3-week infusions of Actemra, seems to be going well with no pain or symptoms for last 6-8 months
• Past: Bi-weekly Remicade (4 years), Methotrexate injections (5 years), Sulfasalazine, Humira, IV Immunoglobulin, cataract surgeries, laser eye surgeries, systemic steroids and local steroid injections to the eye

#Yes4Hope
Words of wisdom

Walk that line between taking your doctor's advice and advocating for your child. You and your child have to live with the consequences. You can, and we have, 'fired' a doctor when their advice just didn't make sense anymore.

I once made Emma write a letter to her future self to explain why she would not take her medicine. She hated it, but it worked.
Yes! Hope GROWS here.