Hey everyone!! Welcome back for episode 22 of Lymphedema Podcast. How awesome was last week's interview with Cam? His story is so inspiring and really demonstrates how much you have to be your own advocate when trying to get treatment for your lymphedema. I hope you all listened to our announcement at the end of the episode…Cam is planning to join us as our guest speaker this summer for our inaugural Camp Watchme weekend!

Today I want to talk about Camp Watchme. Brylan’s Feat, Ninja’s fighting lymphedema foundation and I, Lymphedema Podcast are teaming up to host the first ever summer camp for children with Lymphedema. Last week Amy, from Ninja’s, and I hosted a FB LIVE to Officially announce camp and to give camp details. In case you missed it you can find the replay on either of our Facebook pages, Ninja’s Fighting lymphedema Foundation or Lymphedema Podcast…but if you don’t have Facebook this episode is for you! I am going to give you the 5 Ws of Camp Watchme as well as an action step to help us make this camp a pivoting moment in the lives of these children!

1st W: Who is Camp Watchme for? It is for children with lymphedema. The term lymphedema is all encompassing to include primary lymphedema, secondary lymphedema, and lymphatic malformations. Kids ages 6-17 are welcome to register
now for camp. Every kid is encouraged, and asked, to bring an adult with them. This adult can be a parent, relative or caretaker that will work primarily with the child for their lymphedema treatment. The caregiver retreat will take place at the same location as Camp Watchme. All adults who attend camp will be required to fill out registration and a background check.

The second W: What is camp Watchme? Summer camp is a great opportunity for kids to make new friends, learn new skills, and grow in their confidence as an individual. Often children with lymphedema are not able to attend summer camps due to limitations they physically have or fear of not being able to continue their treatment routine. Camp Watchme is a camp created around those two concerns. There are onsite Certified Lymphedema Therapist to perform any daily MLD or bandaging needed, a schedule with frequent down times to adjust garments or bandages, and even group pump sessions every evening. Physical limitations are no concern for camp watchme, children with all forms of lymphedema are encouraged to attend! Our super amazing recreation leaders are both qualified professionals with experience with adaptive physical education, athletic training as well as a Doctor of Physical Therapy. Your children are our top priority, we promise to give them the best care and provide the most fun atmosphere! Camp Watchme isn’t just for the kids though. I have created this camp with the caregiver in mind as well. As a child living with lymphedema there are a lot of questions, but most of them are relative to the age of the child. For example, most children I work with are not thinking of the consequences associated with not wearing
compression, or not performing self MLD...they want to know how can I play basketball or why doesn’t anyone else look like me at my school. The older the children get, the more they expand their awareness of the disease they are living with....in the meantime their parents or primary caretaker is fretting over if they get a job after school or will they have multiple infections and hospitalizations. This is why the caretaker retreat is crucial to this camp being a success. Every adult that attends with have the rare opportunity to meet others with children with lymphedema, attend educational sessions, but most importantly to watch their child THRIVE among other kids with lymphedema. Parents can share stories, tips, and recommendations for what has or has not worked for their children. Combined sessions with both the parents and children will be the perfect opportunity to practice what was learned in the individual educational sessions. The best example of this is Friday there will be an adult session on the basics of Manual lymph drainage, later the same day we will have a kids session on the basics of self MLD, then Saturday morning to tie it all together we are having a combined session on how to make MLD fun. This will incorporate fun music, MLD, self MLD, plus some singing and dancing! What a better way to start the day! I am really excited about this session! There are more educational sessions throughout the weekend.

The 3rd W: When is Camp Watchme? It is only 39 days away! July 18-21st, 2019. Thursday and Sunday are partial travel days while Friday and Saturday are two full days of fun and learning!
The 4th W: Where will camp be? The beautiful Journey to Healing Lodge in Mead Oklahoma. Mead is just a few miles outside of Durant, Oklahoma located off of hwy 69/75. There is free transportation from the Dallas, Texas area airports. (Love field and DFW international) More details about transportation in a few...

The 5th and final W: Why a summer camp for kids with Lymphedema? Why this summer? Why invite the parents? And to all of those I say WHY NOT!! More specifically, why not create a fun and memorable weekend by bringing kids together that may have never seen in person another child that shared their physical appearance of a swollen arm, leg, or face. Why not teach each of these children that while they may be the only ones with lymphedema where they live but they are not alone in this world! Why not give them the tools and knowledge to take control of their future at an early age by teaching what they can do to manage their condition. Why not show them strong, healthy, and happy patient advocates such as Cam Ayala, Veronica Seneriz, and Amy Rivera who have faced the same fears and struggles as them when they were children, but now as adults are passionate advocates, with families and careers. This summer is the perfect opportunity to stop thinking about this camp as a dream and start putting actions in place to make this camp a reality for those who need it the most. We are intentionally starting small this summer so we can grow into the fullest potential this camp has to offer. As for why invite the parents...that is my favorite question. I would say that anyone listening to this podcast is an adult. From my download data there are not kids downloading lymphedema podcast episodes... The parent or caretaker is the
best way to invest in the future of these children. They are the ones advocating for their
cilds treatment, inclusion in school activities, and in general, parents are the ones
responsible for providing the child's care. Give a man a fish and you feed him for a day,
Teach a man to fish and you feed him for a lifetime. Knowledge is power, and parents
need all the support we can provide. Not only do I want the caretaker retreat to serve as
a way to meet other parents and to learn more about lymphedema treatment, but I want
it to be a safe place where they can relax and take off their parent hat for a while just be
themselves. Relax, read a book, watch the beautiful Oklahoma sunset on the deck or
from the air conditioned living room that is lined with huge windows. Just relax and
watch your child be themselves and have fun.

Those are the 5 W's for Camp Watchme, the first summer camp for kids with
lymphedema in the United States! Let's have a quick recap.

Who: any child with lymphedema ages 6-17, plus one adult

What: the first summer camp for kids with lymphedema in the United States that
provides a caretaker retreat for adults.

When: July 18-21 2019

Where: Journey to Healing lodge just a few miles outside of Durant, Oklahoma. (2 hours
from DFW airports)
Why: Camp Watchme wants to see every child with lymphedema grow in their self confidence, sense of community and understanding of lymphedema through education, inclusion, and well quite frankly just having fun!

There are a few details I want to discuss before wrapping up: the free transportation available from DFW area airports is to limit costs associated with travel. Brylan’s Feat has generously covered registration for each family to attend camp so the financial burden would be lowered. Every family is responsible for their own transportation to camp. I encourage families to carpool if possible, this will allow families to share travel costs and time driving. Transportation from the airport will leave at 2 different times, once you have registered for camp you will later receive transportation information and camp address details to coordinate travel plans.

If your child has a daily routine please bring all materials needed. There are outlets in every private room as well as outlets in the commons of the lodge for pump sessions. All garments, wrapping materials or other supplies are not provided so be sure to bring whatever your child uses on a daily basis. There are two CLTs attending camp to perform daily MLD and bandaging.

If you are coming to camp please share our fundraiser link for family and friends to donate toward. We still have facility fees, supplies, and material costs to cover with only a month before camp. Every dollar donated will benefit these families well past camp.
The knowledge, community and confidence they will gain with go with them for the rest of their lives!

If you are not able to attend camp but would like to donate please do so on our crowdrise fundraiser page. Your support financially will help us to create a more knowledgeable generation living with lymphedema. They have so much potential to change the future of lymphedema treatment...one of these kids could be the one to find a cure for this disease!

I don’t think words can fully describe how invested, passionate and excited I am for this camp and for these people! Please help me make this inaugural camp a success! Search for Camp Watchme (spell) on crowdrise.com or follow the link on any of my social media platforms….oh and I am new to Twitter so you can now find me there @lymphpodcast!

https://www.crowdrise.com/o/en/campaign/camp-watchme/bettywestbrook1

Mother Teresa says “Loneliness and the feeling of being unwanted is the most terrible poverty” This podcast is here for you to find friendship and a community for your journey with Lymphedema.

I hope you enjoyed learning more about Camp Watchme. Email me with your story if you would like to share. Lymphedemapodcast@gmail.com or visit the website lymphedemapodcast.com to submit a topic for another episode.