Grassroots Advocacy

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Advocacy

**Advocacy** – The discipline of representing and promoting the rights and interests of a vulnerable person or group of people. Advocacy is often part of the mission of an organization.

**Legislative Advocacy** – Refers to efforts to influence, or persuade a political system. Legislative advocacy is usually a function of an organization that supports the overall advocacy role within the mission.

**Education** – Providing information to legislative bodies to enable them to make informed decisions. Many non-profit organizations or government entities are prohibited from engaging in lobbying, and often times legislative advocacy, so they “educate.”
Advocacy Guidelines

1. Avoid partisanship
2. Know your audience
3. Have an advocacy plan
4. Share data – data matters
5. Create a memory
Targeted Advocacy

**Knowledge is power** – Knowledge about your constituency (scleroderma patients), and knowledge about your target audience.

**Timing is everything** – Know when to approach a person or group, and know how to schedule appointments.

**Build alliances** – There is strength in numbers. Build alliances with other groups to support each other and to have legislative influence.
Shelley’s Story

- Symptoms - It took a decade
- Welcome to the club. 2009 Systemic Sclerosis
- From employment to disability
- Educating and advocating to bring awareness
• Oh the places you will go, and the people you will meet!

• Experience as a Group Leader
Dee’s Story

Three local kids help save mom's life

by Maggie O’Mara
Bio | Email | Follow: @maggiektvb7
KTVB.COM
Posted on January 16, 2012 at 1:26 PM

Three local kids are being called heroes by the Boise Fire Department. They did the right thing in an emergency, and helped save their mom’s life!

Maggie O’Mara introduces us to these “hero kids” in 7’s HERO.

Hero Kids

by Maggie O’Mara
Bio | Email | Follow: @maggiektvb7
KTVB.COM
Posted on January 17, 2012 at 8:16 AM
Updated Tuesday, Jan 17 at 9:24 AM

It was a holiday weekend, so I'm not sure if you caught my Seven's Hero on Sunday night. If you missed it, I think you'll really enjoy it. I interviewed three local kids under the age of NINE, who acted quickly in an emergency and most likely saved their Mom's life. They were honored last week at Fire Station 14 for their bravery and quick thinking! I was really impressed with them, and with what they did at a very scary time for them. It just goes to show that emergency education for kids really works.

Take a look:
My Experience with Grassroots Advocacy


2. Attended the Scleroderma Foundation Patient Education Conference in New Orleans in 2016. (Met Washington Evergreen Chapter board members)

3. Wrote to my House and Senate representatives in Idaho upon returning home to Idaho from New Orleans Conference.
August 24, 2016

The Honorable Mike D. Crapo
United States Senate
239 Dirksen Senate Building
Washington, D.C. 20510

Dear Senator Crapo,

I am 43 years old, the wife of a Vetran, a mother of three young children, and I have Scleroderma. As a person who went through several years of testing and medical procedures before being diagnosed with Scleroderma, I now advocate on behalf of others who have had the misfortune of being diagnosed with this life altering condition.

Scleroderma is a chronic connective tissue disease that has no cure. It can be extremely debilitating, causing severe physical and emotional pain, and often results in economic hardship for those with whom it affects.

In my case, I had to undergo several medical tests and procedures, requiring frequent travel outside the State of Idaho, which caused the affliction of additional stress and anxiety upon my family. It is not uncommon for people who suffer from Scleroderma to get misdiagnosed, to experience insurance delays, or to face a medical system that is not properly educated about the condition.

Sadly, it often takes too long for patients to get an accurate diagnosis, significantly reducing the lifespan of a Scleroderma patient. Research, education and advocacy is critically important in developing earlier diagnosis and treatment options. I urge you to support the Scleroderma and Fibrosis Research Enhancement Act (H.R. 3666).

Sincerely,

Dee Burlile

September 1, 2016

Dee Burlile
2965 S Appia Ave
Meridian, ID 83642-7651

Dear Dee:

Thank you for contacting me with your support regarding increased support and funding for the National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health (NIH). I share your support for NIH research and welcome the opportunity to respond to your request.

As you know, scleroderma is a chronic disease affecting nearly 300,000 individuals in the United States alone. Often referred to as a single disease, scleroderma is more accurately understood as a symptom of a group of diseases that involve the abnormal growth of connective tissue. In some forms of scleroderma, hard, tight skin is developed, while other forms of the disease involve damaging effects to blood vessels and internal organs, such as the heart, lungs and kidneys.

In March 2016, I joined with Senator Robert Casey (D-Pennsylvania) and Senator Richard Burr (R-North Carolina) in requesting robust funding for the NIH in Fiscal Year (FY) 2016. In December 2016, Congress enacted legislation providing $32 billion in FY 2016 funding for the NIH, an increase of $2 billion from the previous year. Congress is currently working on appropriations measures for the coming fiscal year.

I have consistently supported research geared towards understanding and treating diseases that affect countless Americans, and will continue to do so. I remain committed to increasing funding for essential medical research so that we can better respond to the needs of patients nationwide.

Again, thank you for contacting me. Please feel free to contact me in the future on this or other matters of interest to you. For more information about the issues before the U.S. Senate as well as news releases, photos, and other items of interest, please visit my Senate website, http://crapo.senate.gov.

Sincerely,

Mike Crapo
United States Senator

Microsurgery
4. Wrote to Minnesota Vikings NFL team about positive experience I had while receiving treatment in Seattle
It then occurred to the Idaho native that there was a preseason game in Seattle Thursday, and the men a few feet from her were Vikings players. Before she knew it, Burlilé was starting up a conversation with the group that included defensive teammates Linval Joseph, Everson Griffen, Captain Munnerlyn, Anthony Barr, Tom Johnson and Shamar Stephen.

"I just kind of get right in there," Burlilé said, laughing. "It doesn't really quite matter my size – I'm not really shy."

While the Vikings caught Burlilé's attention, she also drew theirs when they noticed she was using a walker to maneuver around. One of the players inquired about her condition, and Burlilé was happy to explain that she was in Seattle to receive treatment for Scleroderma, a progressive, chronic, connective tissue disease that causes hardening of the skin and internal organs.

"When people ask me, I appreciate that they're brave enough to ask me what's going on – most people won't, because they want to avoid the question," Burlilé said. "I felt kind of honored that they dove right in there and asked, and that was kind of flattering to me."

"The fact that they respect me enough to listen to what I had to say was equally important to me," she added.

Oftentimes, patients with Scleroderma go years before being diagnosed. Burlilé struggled with symptoms, various treatments - including four back surgeries - and numerous hospital stays over a long period of time. At one point, Burlilé had a seizure while at home with her three young children. It was then that she realized something was significantly wrong and started the search for a diagnosis, which she received within this past year.

Burlilé said it's often easy to feel isolated and be overcome with self-doubt and discouragement, but the experience with the Vikings players left a major impact on her.

"It's [incredible when] people make the effort and take the time to care and really go out of their way to make you feel like you're still in this game," Burlilé said. "I feel so honored that they listened and took the time with me."

As a lifelong football fan who grew up cheering for the Boise State University team, Burlilé has come to have such an appreciation for the game and the athletes who play it. She's part of a Scleroderma advocacy group back home in Idaho, and the group coined the phrase "We've got skin in the game" as its slogan. The members who are fighting to find a cure for Scleroderma often use the game of football as their frame of reference when raising awareness about the disease.

"I admire that [the players] put in time and effort and have to put in the agility and strength to do what they do," said Burlilé. "I also have to have the agility and strength to fight this ugly disease."

Burlilé is continuing her efforts this week on Capitol Hill, where she will join the Scleroderma Foundation to urge members of Congress to support the Scleroderma and Fibrosis Research Enhancement Act (H.R.366). The bipartisan bill seeks to coordinate and advance research in fibrotic illnesses, using Scleroderma as a prototypical condition for research due to its manifestation throughout the body.

Burlilé, who's "absolutely a Vikings fan" even more so than she was before, said that her interaction with the Vikings boosted her morale and motivation to continue fighting for a cure.

"Every time I look at the picture taken with the Viking players, it makes me smile," Burlilé said. "I think to myself that with this kind of defense standing with me, my days fighting Scleroderma seem a little easier."

The Scleroderma Foundation helps people with Scleroderma – and their families – cope with the disease through support programs, physician referrals and educational information. To learn more about Scleroderma or help raise awareness and research funds, visit www.scleroderma.org.
7. My family has been actively involved in bringing about Scleroderma Awareness in the state of Idaho.

**Free Verse**

I am feeling low and unhappy  
because my mom is sick and she is not getting better.  
I hope my mom gets better very soon.  
I love her more than anybody in the world.
My son’s essay and his HOPE for Health Care:

3. Topic for your personal essay (not to exceed two pages single spaced):

- Francis had a special message at the Super Bowl this year that said “...it is possible to build a culture of encounter and a world of peace... we learn to sacrifice, to grow in fidelity and respect the rules.” Please write about your hope for a world of peace, be specific about current events, and what you are going to do to be part of the change.

As a Catholic and as an athlete I was excited to hear that Pope Francis was giving a message during the Super Bowl. After listening to his message and reading this essay topic, I thought a lot about my hope for world peace, current events, and what I would do to be a part of the change.

One of the ways America could help with world peace would be to make friends around the world. To make friends around the world America could help provide healthcare in countries that lack good healthcare. The best way to make sure that countries are receiving the healthcare assistance they need would be to send doctors and medical supplies to countries in need. My hope would be that the countries that received our help would be grateful for our help and would maintain peace with our country, and then be peaceful towards other countries.

As I watch current events I see a lot of fighting between countries and a lot of healthcare problems around the world. I see healthcare as a need that everyone has and I also know that people always appreciate good medical care. If our country could improve our health care system and help other countries meet their health care needs, then it may be easier to achieve world peace.

The way that I would be part of the new changes is I would become one of the health care providers. I have seen my mom suffer with a lot of healthcare problems, so when I grow up I want to be a physical therapist. As a physical therapist I could travel to other countries and help injured people strengthen themselves so they could recover from injuries. I realize that world peace would be hard to achieve, but with enough support it could happen.

“If our country could improve our health care system and help other countries meet their health care needs, then it may be easier to achieve world peace.”
Gage Burridge
June 13th, 2017

Dear Mr. and Mrs. Carley,

I would like to thank you for giving me the scholarship to attend Bishop Kelly High School. It really means a lot to me that I will be attending a high school that I have always wanted to go to. I have wanted to go to Bishop Kelly because I am a Catholic who goes to Holy Apostles Catholic Church and I have also heard that Bishop Kelly is known for their good education, with a 100% graduation rate and 98% who go onto college.

Also, as I explained in the scholarship application, my family and I have been through some rough times, having to deal with traveling out of state for my mom and sister’s health, and having to move to different houses in the past 5 years. So with this scholarship, it will help provide some relief for my family.

I will be honored to be a Bishop Kelly Knight. I understand that being a Bishop Kelly Knight takes hard work, dedication, and stepping up to the challenge. I promise that I will work hard and value your generous gift. Thanks again for your help.

Sincerely,

Gage Burridge
Handouts & Examples

- Elevator speech
- What to Expect During Capitol Hill Advocacy Day
- Personal examples (letters, family involvement, etc.)
What Can I do Now?

- Practice your Elevator Speech

- Develop and write your story

- Develop a plan with your Support Group to create a local Advocacy Day to meet with representatives

- Webinars hosted by National Scleroderma Foundation to help with writing templates and advocacy workshops

- Contact Shelley or Dee for upcoming events
Healing the Mind, Body, and Spirit

AACHOO!

GOD BLESS YOU

What is Scleroderma?
Scleroderma is a chronic often progressive autoimmune disease like rheumatoid arthritis, lupus, and multiple scleroderma in which the body’s immune system attacks its own tissues.

The disease, which literally means “hard skin” can cause thickening and tightening of the skin, along with serious damage to internal organs including the lungs, heart, kidneys, esophagus, and gastrointestinal tract.

Symptoms of Scleroderma vary from mild to severe. For some, it is a life-threatening disease. For most people with Scleroderma, the disease has a serious impact on daily life. And although medications can sometimes help there is no cure yet.

Do Your Hands Hurt?

Stay safe

Seasonal Allergies

POISONS TO AVOID

Scleroderma Foundation

June is Scleroderma Awareness Month

No matter how you feel, get up, dress up, show up. Never give up.