Grassroots Advocacy Webinar #2: Preparing And Sharing Your Elevator Speech
by Dee Burlile, M. ED and Shelley Van Pelt, RN, MSN, CNS
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Elevator pitch, elevator speech or elevator statement are short sales pitches. An effective elevator speech is a summary that quickly and simply defines a process, product, service, organization or event and its value.
HOW TO PREPARE AND CRAFT AN EFFECTIVE ELEVATOR SPEECH

It takes time and practice to get your pitch right. You will likely go through a number of drafts before you find the right words and examples that feel comfortable.

You may have several versions depending on the context and to whom you are presenting. Here are a few tips to help you prepare:

- Write your story – keep it short.
- Write your story several different ways.
- Write down your objective or goal.
- Write your story in brief bullet point format.
- Let it sit.
- Highlight the “good stuff.”
- Put the best pieces together for this audience.
- Time yourself speaking from your notes.
- Record yourself and watch it.
WHO, WHAT, WHERE, WHEN AND WHY?

The order may change, but the objective should always remain the same.

**WHO are you?**
- You are an advocate, a parent, a sibling, a veteran, a medical professional, a teacher, a skydiver.
- When presenting to a policy maker or legislative body, you represent the Scleroderma Foundation.
- Be brief yet compelling (you want them to remember you!).
  - Example: I am *(your name)* and a *(title)* from the *(your state of residence)*, and I am here with the Scleroderma Foundation.
  - Example: I am the mother of a child with scleroderma, and I struggle with getting health care for my child.

**WHAT is your connection to scleroderma?**
- I am a caregiver for a person with scleroderma.
- I am a patient advocate in town to bring awareness on behalf of people with scleroderma.
- I am a patient educator for people living with scleroderma.

**WHERE do you pitch your elevator speech?**
- Everywhere! Share it with family, friends, and neighbors, and especially with your elected officials.
- The opportunity to share your story may present itself at the grocery stores, in restaurants, during youth activities, at PTA events and at work.

**WHEN do you pitch your elevator speech?**
- Anytime that is appropriate. Use good judgment when approaching someone.
- If you have a scheduled appointment, you are more likely to have someone’s undivided attention.
- When possible, share a Scleroderma Foundation brochure or your business card. Have resources on hand you that you can leave behind.
- Be willing to ask for their contact information.

**WHY do you pitch your elevator speech?**
- I am part of a group from the Scleroderma Foundation in town to advocate and bring awareness on behalf of people with scleroderma.
TIPS ON DELIVERING AN ELEVATOR SPEECH

- Make a brief statement
- Be confident and know your material
- Body language and eye contact
- Voice inflections
  - Slow down and speak clearly
- Be relevant and real
- Avoid jargon
- Make sure it invites a conversation
- Practice!
  - Practice!
  - Practice!
Hello, I’m Shelley Van Pelt. (who)

I am a medical and education outreach coordinator with the Washington Evergreen Chapter, and I am also an advocate for patients with scleroderma. (what)

I came to Representative Smith’s local office (where) today (when) to advocate for the House bill to support funding.

The webinar is hosted by the National Scleroderma Foundation to help patient advocates to prepare and share their stories with scleroderma. (why)
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 Veteran, 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,

Dec Burlile
OPPORTUNITIES

Seek Opportunities
Find Commonalities
Build Relationships
Recognize the Teachable Moments
Follow up! Follow up! Follow up!
September 7, 2016

Ref: Scleroderma Awareness

Dear Vikings:

As an advocate for the Scleroderma Foundation I want to share a recent experience I had with some of your players while I was in Seattle for medical treatment for Systemic Sclerosis/Scleroderma. On the evening of August 12th I had dinner at the Blue Acre Seafood restaurant in downtown Seattle, and was thrilled to encounter several of your players.

Meeting Minnesota Vikings players was particularly special to me since I was originally diagnosed with Scleroderma at the Mayo Clinic in Rochester, Minnesota. Some of the players I met were: (#92) Tom Johnson, (#55) Anthony Barr, (#98) Linell Joseph, (#97) Everson Griffen, (#60) Shamar Stephen, and (#24) Captain Munnerlyn. All six of these players were very friendly and helped brighten a day filled with treating Scleroderma.

Scleroderma is a progressive chronic connective tissue disease that causes hardening of the skin and internal organs. There is currently no cure for this disease, but through increased awareness and expanded research, quality of life can be improved.

I am interested in writing an article in the October edition of the Scleroderma Foundation newsletter. I would like to mention the positive experience I had with members of the Minnesota Vikings players. I have included one of the pictures taken that evening and would like to include this photo in the article.

If the Minnesota Vikings would be interested in learning more about Scleroderma and helping to raise awareness, I would love to help connect the Scleroderma Foundation with team officials. Please pass along my thanks to the players for making this evening such a memorable experience.

Sincerely,

Dee Burtle
"I just kind of get right in there," Burille said, laughing. "It doesn’t really quite matter my size — I’m not really shy.

While the Vikings caught Burille’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 Burille 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," Burille 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. Burille struggled with symptoms, various treatments — including four back surgeries — and numerous hospital stays over a long period of time. At one point, Burille had a secure white 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.

Burille 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," Burille 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, Burille has come to have such an appreciation for 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 Burille. "I also have to have the agility and strength to fight this ugly disease."

Burille 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 Fibrositis 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.

Burille, 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 Vikings players, it makes me smile," Burille 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.
MISSED OPPORTUNITIES

Be Bipartisan
Be Prepared
Be Respectful
Help others to feel comfortable with your condition.

- Prosthetics
- Walker
- Oxygen
- Skin Pigmentation

Invest your time with people.

Follow Up.
THE ART OF THANK YOU NOTE WRITING

When to Write a Thank You Note:

1. There's never a wrong time to write a thank you note.
   Sending a thank you note through the mail shows effort. It demonstrates that you took the time to put pen to paper, addressed an envelope and bought a stamp. It's tangible. They can touch it, hold it, reread it, share it and display it. A personal correspondence makes your thank you far more sincere.

2. Always write a thank you note as soon as possible.
   Send it within two weeks of attending the event or receiving the gift.

3. Send a thank you note through the mail.
   Email thank you notes are certainly convenient, but they are not always appropriate.
Dear (Representative),

Thank you for meeting with me and other patient advocates representing the scleroderma community earlier this month. As we discussed at that time, scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The most common manifestation of the disease is hardening of the skin, however, the disease can cause fibrosis in nearly any organ system, making it a prototypical disease for study.

As we discussed during our meeting, I am 43 years old, the wife of a Veteran, and a mother of three young children. I personally had to undergo several medical tests and invasive procedures before being accurately diagnosed with Scleroderma. I now rely on my husband and three young children to help with my care, and use my walker on a daily basis. Additionally, I continue to struggle with delays and denial of coverage from my insurance companies for various medical care necessary in treating Scleroderma, which has ultimately resulted in the loss of our family home.

In this regard, I wanted to follow up with you regarding the Senator becoming an initial cosponsor of the Scleroderma and Fibrosis Research Enhancement Act (H.R. 3666), being led in the Senate by Senator Kirsten Gillibrand. This legislation will coordinate and advance fibrosis research activities within the National Institutes of Health (NIH) by establishing the National Commission on Scleroderma and Fibrosis Research to develop a long-term plan on opportunities and challenges in fibrotic disease. The bill does not include additional funding or mandates for NIH and will likely be scored as de minimis. Congressman Peter King and Congresswoman Lois Capps are leading this effort in the House.

Your office can become an initial cosponsor of this important legislation by contacting Alyson Northrup (Alyson_Northrup@gillibrand.senate.gov) in Senator Gillibrand’s office.

On behalf of the community of folks affected by scleroderma, thank you for your time and consideration of this request.

Sincerely,

Name
Address
Address
Phone
email
Thank You!  

Dee Burlile <dburlile@gmail.com>  
To: richard.coles@mariott.com  

Mon, Sep 26, 2016 at 3:34 PM

Dear Richard,

I was a recent guest at the Residence Inn and would like to thank you for your professionalism and your efforts to ensure that my stay was pleasant. If you remember, I was the guest who used a walker and had a HVAC issue in my room. I appreciated your attentiveness to my needs and the fact that you treated me with dignity and made the extra effort to ensure that my needs were met. In addition to being extremely hospitable at the hotel, you also walked me to the Renaissance and introduced me to restaurant staff, where I was again treated like a welcomed guest.

During my stay at the Residence Inn, I was part of a Scleroderma Foundation group that was visiting Capitol Hill to urge members of Congress to support legislation on behalf of people with chronic illnesses. As a person with a chronic illness, I often have challenges with activities of daily living. It is people like you who help improve the quality of life for people with disabilities and I want to thank you for making my stay at the Residence Inn such a pleasant one, and I am going to encourage the Scleroderma Foundation to Patronize Marriott properties for all meetings and conferences.

I have also written to the Marriott Corporate offices to make sure they know what a total gem they have working for them. I hope all is well with you!

Sincerely,

Dee Burlile

Message from Marriott Customer Care [ ref: 00D37JC9y_500375BjwT:ref ]

Message  

Hello Dee Burlile,

It’s great to hear about the exemplary service you received! Exceptional associates who exceed guest expectations are a source of pride at Marriott. I will share your delightful message to make sure Richard Coles will be recognized.

Thanks again for your message. You made my day!

Safe travels,

Maria Davis,
Marriott Customer Care

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Original Message

From: dburlile [dburlile@gmail.com]  
Sent: 9/26/2016 4:30 PM  
To: customer care@mariott.com  
Subject: Richard B. Coles, Residence Inn Arlington Capital View

customer care@mariott.com  
http://www.marriott.com/realhelp/rewards/custservrpt.mi  
Complaints/Concerns about previous hotel stay

Dee
Burlile
Dear Vikings, 9-19-17

Thank you all so much for the care packages! I can’t wait to frame them and then put them on my wall, and we were so excited to see the packages were from you guys. I really enjoyed watching the PreGame in Seattle! You guys did really good! My family and I really hopes you guys make it to the Super Bowl! It would be really cool to meet you guys!!! You guys are really good at football, and it’s really cool my mom had the opportunity of meeting some of you!

Thank you, and love,
Alyssa Burlile ♡
WORKS CITED

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