RERC *on* AAC

The sky is only the beginning: Living life without limits

Godfrey Nazareth
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Janice Light: So I'm really excited to welcome Godfrey Nazareth here, Godfrey has a masters degree in biomedical engineering he himself is definitely an expert user of augmentative and alternative communication and has more than a decade of experience. You're just starting to get old Godfrey. [laughter] And definitely expertise in research and development of medical and other assistive technology devices. He currently serves as a volunteer research engineer and scientist in urology at the children's hospital of Philadelphia (CHOP) and as a volunteer research engineer for Philadelphia pediatric medical device consortium that provides clinical business and regulatory expertise in seed funding to translate innovative ideas into commercial products to support children with medical needs. He has a huge amount of experience in successful tech transfer and was previously the manager of a product development for a company that commercializes break through technologies from research at the University of Pennsylvania center for bioactive materials and tissue engineering. He's going to be working with us on the RERC on AAC and brings definitely a unique combination of rehabilitation and biomedical engineering expertise and personal experience as someone who uses AAC. He's also got a wonderful wife and a very cute daughter who is now in grade two. Oh my God we are getting old. [laughter] … So Godfrey will be working as the co-leader of training and dissemination on the RERC with David. So welcome Godfrey we are just so pleased that you could join us today. And this group are a group of masters level students who are training to be speech-language pathologists who are doing standard competencies and taking additional coursework to really develop specialized expertise in the area of augmentative and alternative communication so they will be going out to work with children and adults who rely on AAC and their families. About half of them are in their second year and about half of them are in their first year of a two-year program.

Godfrey Nazareth: Hello everyone as you can probably tell I am speechless with excitement to begin among the world's finest graduate class of speech-language pathologists. [laughter]. Thank you so much for having me over I am incredibly grateful to Dr. Janice Light for this wonderful opportunity. I am happy to share with all of you some of my stories and a glimpse through my perspective on AAC. As a child, I loved to talk and yap away at every possible

opportunity I could get, at school my talkative nature and my nonstop questions were the bane of many of many of my teachers existence especially Sister Mercy my English teacher who I nearly gave a nervous breakdown [laughter] spirit and constant interruptions. On one occasion fighting back the tears, Sister Mercy asked me, “Godfrey do you think there may be a reason you have two ears and just one mouth?” [laughter].

I think speech language pathology is one of the noblest professions in existence precisely due to the reason that we have got the proverbial five senses but only one voice. When voice and speech gets suppressed for any reason the input of information far exceeds our input leading to a state of chaos and confusion in the human being. Speech language pathologists help empower individuals find their voice a role which puts each one of you in a place of incredible power and of great responsibility. I know with my charming personality and my fabulous accent and my almost Greek-God like features [laughter] its hard to place me. I originally belong to the beautiful country of India. I am a biomedical engineer and a research scientist by profession in addition to designing medical devices and formulating pharmaceuticals some of my passions include the great outdoors, aviation, robotics, music and theatre, linguistics and semantics serving as research value in anesthesiology and critical care medicine at the children’s hospital in Philadelphia, my work with the RERC AAC and my family. Not a long time from today when I was still young and dashing graduate student during my masters in biochemical engineering at Drexel University I begin to notice subtle changes in my balance and my speech in addition to the challenging and often humorous consequences at enunciating certain words. People around began to think I was probably partying too much and assumed I was perhaps in high spirits. Some of my friends who were familiar with my sense of humor and my talents in mimicry thought it was all one big funny act and I played along.

However, about a year into my studies I was diagnosed with a rare, fatal neurodegenerative condition the prognosis was very bleak and there was no treatment or cure. The silver lining was not having any chemo or painful surgeries for my condition. At this point I was still halfway from graduation, there was not time for denial - times there was dark and deep but there were loans to pay and promises to keep. To cut a long story short I sped up my studies and graduated almost a year in advance. I found a job just in time before the symptoms became more prominent. As months and years went by I felt a deepening void within me resonating with lyrics of a Neil diamond song - I am I said and no one heard at all not even the chair, I almost cried I’m so lost and I can’t even say why. With my training as a biomedical engineer I was able to come up with a variety of strategies to facilitate communication including putting together my very own devices to help me to function as a high level professional and dedicated family man. After several tests, evaluations, biopsies and scans lasting over nearly a decade my condition was diagnosed as an atypical form of ALS unique only to me and although the road has been very tough on many levels my wonderful team of doctors continue to be amazed with the level of activity that I am able to pursue.

Today, I'm working on several exciting and novel technologies in addition to concepts for economically priced next generation AAC devices and technology. One of my current projects is to substantially shrink the enormous and extremely expensive surgical microscopes used in various delicate surgeries such as neurosurgery, ophthalmology and microsurgery. It is almost an oxymoron if you will to refer to these systems as microscopes. The digital version that I'm working to build not only offers advanced features and portability but it comes at a fraction of the cost of the larger optical systems. It promises to bring disruption at a global scale and transform the way a surgeon looks at surgery literally and figuratively.
I was deeply moved by a poignant question raised at the 2012 AAC state of the summit conference about patients with ALS requesting to be taken off the ventilator. I have been thinking since then of what can be done for individuals with locked in syndrome and patients with physically debilitating neurodegenerative conditions. The gentleman in this picture as you may know is Stephen Hawking smiling ear to ear while floating in zero gravity and even though Dr. Hawking has been battling ALS for over four decades he surely seems to have found the allusive thing that Victor Frankly calls meaning in life. In spite by the basic tense of logotherapy and Abraham Masslow's seminal work on the hierarchy of human needs and humanistic psychology I'm working towards concept devices for a line of technology combining my passions in assisted technology, robotics, neuroscience, and aviation I have grown to lead up this design of assisted aviotics to any individuals with significant physical disabilities and debilitating neurodegenerative conditions to pursue flight training with safety and a step further, this may very well seem utopian today to have a choice for them to pursue the possibilities of a career in aviation. I also find that assisted aviotics can be used as a beautiful metaphor to symbolize the strategies, no pun intended, for rising above the established paradigms of what is believed to be possible for individuals with significant disabilities and their employment options.

As da Vinci famously exclaimed for once you have tasted flight you will walk the earth with your eyes turned skywards, for there you have been and there you will long to return.

Once again, thank you so much Dr. Light for this incredible opportunity and to each one of you for allowing me to share my perspective on AAC. Although at times, I do miss my original deep baritone voice I have been using AAC technologies for many years now and in the process having a lot of fun with them. I am sure Sister Mercy would be impressed. I do not believe in any limits, there are several frontiers the sky is only the beginning.

Janice: So I take it from you're slides that you are open to questions. So questions for Godfrey. Lee

Student: So we know you have had a big role in kind of bringing out your own AAC systems, how big of a role do the SLPs have with working with you?

Godfrey: Great question. Thank you so much for asking. I had already built my own prototype systems that convert text to speech long before I knew it was called an AAC system I had met with a few SLPs but obviously they had not done their training here at Penn State none of them indicated to me the world of infinite potential that could open up even if I was not responding to exercise and treatment. I guess this is one of the reasons why I have become and evangelist for AAC technology.

Janice: So is it your outfit your using right now Godfrey or are you using a commercially available app.
Godfrey: I am using a customizable free app

Janice: And I know you use social media a ton, I see you on Facebook. Do you use an alphabet board at home too or do you mostly use your IPhone?
Godfrey: I have a variety of devices including a couple of tablets, my PC and an old laptop

Janice: You've got all kinds of things. Small, medium and large. [laughter] Other questions.

Student: Are you bilingual? And how does AAC adapt to your bilingualism?

Godfrey: Unfortunately as of now, not very well.

Student: What are the biggest challenges you face

Godfrey: There have been several challenges the toughest one so far would be the process of job applications and interviewing. I've had interviews last for over six hours.

Janice: Other questions for Godfrey

Student: First, thank you for sharing all the wonderful pictures of your daughter, she's adorable. I was wondering if you would be willing to share some thoughts and experiences on the use of AAC to communicate with your family

Godfrey: Wonderful question. As time goes by it's getting much easier to communicate with my family. With smartphones life has become so much more convenient. That is of course, if the phone is not being oversmart. I put my daughter to bed each night with beautiful songs and she will not allow me without my phone or tablet. I keep in touch with my wife throughout the day on whatsapp. I use skype to communicate with my extended family back home. AAC augments my communication but I have always believed the real communication with family is through the heart far beyond the evolution of words or technologies.

Student: I have a question. So one of my very good friends has a neurodegenerative disease and I was wondering what's some advice you would give to her when symptoms start to present themselves or to me as her friend and an SLP.

Godfrey: That's a great question.
First, don't lose hope. Neurodegenerative diseases can be daunting. The way I find being in the manifestation of painful symptoms is perhaps best epitomized by good old Rocky Balboa, the Philadelphia Boxer. It ain't how you hit, but how hard you get hit and keep moving forward, how much you can take and keep moving forward. My heart goes out to your friend, but encourage her to keep her hopes high and to pursue a dream new, a dream that may seem impossible today can very well become tomorrow's reality.

Student: A question. Super interested in all the new ideas for all the new technologies invented and I know we definitely don't have time to go through all of them I'm sure but I was curious about the wearable one that you had invented and what you kind of, what you see that looking like maybe a little bit?

Godfrey: I do not have a photo right now on my laptop so I'm going to have to use a 1,000 words. Wearables would include a line of devices much like the smartwatches integrated with multisensory inputs and with intelligent artificial intelligence software. technology is shrinking at an exponential rate. devices are going to get smaller better faster and cooler.

Janice: So we have time just for one more question. Godfrey I'm going to seize the floor. So this group are about to go out in the real world and try to make a difference in the lives of kids and adults who rely on AAC and their families. What recommendations would you give to them as they transition out of here and into their next, their next lives beyond Penn State?

Godfrey: Beautiful question, Dr. Light. When an individual is faced with a communication disorder, it impacts everyone from the individual to his family to the society. I would encourage each one of you to look not just at the person but look at the impact your work is going to have on the family. You are transforming society one individual one family at a time. Everyone has got a deep and powerful story to share. Thank you so much for choosing to help people to find their voices.

Janice: That's great advice, Godfrey. I can't thank you enough for coming up and spending the morning with us. For me every year when you come it's like the highlight for me of that semester and that year. Professionally I always take away so many lessons from what you have to share with us and I think beyond that on a personal level, Godfrey, you have such an inner peace inside and you find so much joy in life and I think for me I always look at that and think these are such valuable lessons for me and for all of us on a personal level to take away, so thank you so, so much.