

## Winter 2016 Newsletter

### Children in Ethiopian Capitol Receive Treatment

Healing the Children, a Philadelphia-based organization that provides healthcare globally, sponsored two ear, nose and throat (ENT) doctors, Drs. Casselbrant and Issacson, to travel to Addis Ababa in Ethiopia for six days at the end of 2014 to perform ear surgeries on Ethiopian impoverished children. Patients were so ill that they were in danger of losing their hearing and the disease becoming deadly.

"These children have an enormous need due to poverty, disease, malnutrition, ear impaction and fluid behind the eardrums," says Dr. Margaretha Casselbrant, Medical Director of the Society for Middle Ear Disease (SMED) and Director of the Department of Pediatric Otolaryngology, Children's Hospital of Pittsburgh.

Operating out of the CURE Hospital, Dr. Casselbrant, along with long-time colleague, Dr. Glenn Isaacson, Director of Pediatric Otolaryngology at Temple University School of Medicine, treated perforated eardrums and other sequelae of



**Makanisa School for the deaf**

suppurative otitis media. They performed bronchoscopies (to examine airways), mastoidectomies, (to drill and aerate bone and remove infectious tissue in the mastoid bone), tympanoplasties and myringoplasties (to repair ear drums).



**Resident soft-tissue training**

In addition to treating children and performing surgeries, the two ENT specialists trained local doctors. Five residents were assigned to the operating room, and five to treat

patients in the outpatient clinic. The hope is these doctors will be able to continue this work in the future. "There were only ten ENT doctors in



the whole of Addis Ababa, in a city of over 3 million people," says Dr. Casselbrant.

When you go on a medical mission, it is not unusual to have less equipment. In the CURE Hospital, "The people [physicians and nurses] were very well-educated, but the equipment was simple and old. We had to work with less, but we had what we needed." The team worked very efficiently and accomplished a lot in a short amount of time.

The two ENT doctors also brought hearing aids to children attending Makanisa School for the Deaf in Addis Ababa, and examined their ears. "We really loved the interaction with the children," says Dr. Casselbrant.

It wasn't all work, as she found time to go to the theatre to watch traditional Ethiopian dances. "They wore beautiful, colorful dresses, both men and women."

The mission was so enjoyable that Dr. Casselbrant returned to Ethiopia in November 2015, and will be speaking at a conference in Egypt in December 2015.

## New ENT Clinics Being Established in Madagascar, Zambia, and Malawi

"Towards the end of my working life, I developed a vision for trying to do something to improve services in Zambia, Zimbabwe and Malawi," said Dr. Christopher Prescott, in an e-mail. An ear, nose and throat (ENT) outreach program is being established in several Central African regions, "where such services are desperately needed."

Originally from Zimbabwe, Dr. Prescott spent most of his working life – after a somewhat extensive and varied training – as a Paediatric ENT surgeon in the Red Cross War Memorial Children's Hospital in Cape Town, South Africa.

Now, he is setting up training programs for ENT surgeons at various mission hospitals. Three graduates have returned after training outside the country "to strengthen the pool of expertise," he explains. "Eight doctors are enrolled in the program with the first two graduates emerging next year."

The clinics are part of a chain, known as "Centres of Excellence." Funding has been found to help these Centres provide audiological services since there is a desperate shortage of audiologists, according to Dr. Prescott.

Three of the Centres are sponsored by Christian Blind Mission (CBM). The German charity has established a mission hospital in Lusaka, Zambia with an ENT surgeon and an audiologist. "Historically, the CBM has been concerned with blindness

but now is developing an interest in ENT – particularly with respect to deafness."

A military hospital in Madagascar is in high demand for ENT services, so another rudimentary "Centre" will open at a mission hospital with an ENT surgeon and a physician audiologist. Training in this country is extremely limited, with none at the community level in primary ear and hearing care.

"The ear and hearing care situation in Madagascar is heartbreakingly appalling with only one functional ENT service in the Capital, at the military hospital assisting with ENT training," he says, adding that the five trainees have an excellent trainer.

The University Teaching Hospital ENT unit in Madagascar has moved to a new hospital, "but with no equipment so is virtually non-functional." He estimates that 30 sets of basic audiology equipment will be needed for physicians.

"Equipment comes at a cost of about half a million dollars per unit by the time the facility is renovated. Ten of these [units] are needed for the ENTs already out there and non-functional for lack of equipment, and the five in training at present who face the same [issue]."

"Two million people in the country [suffer from] a hearing problem, of whom 800,000 have chronic ear disease, 200,000 are deaf, and of those, only 3,000 have been able to get educated through deaf schools."

The Lutheran Church Ear and Hearing unit, outside Antananarivo (the capitol), is one of the few places in the country offering ear surgery and hearing aids.

"A very good ENT surgeon was sent up to a university hospital in the far north but without any equipment," states Prescott. "Twenty audiology physicians are trained but are sent back to their hospitals with no equipment," adding that another ten are also in training.

Equipment such as solar-powered otoscopes are low-cost (\$10) and simple, but highly sought-after tools for removing earwax. These could be used by 30,000 community workers to treat a very common cause of hearing problems, earwax buildup.

Training lay individuals and professionals is not as expensive as equipment, according to Dr. Prescott, but funds are needed. "The government can hardly afford to pay the low level salaries that it needs each month. There is hardly anything left over for development."

The third Centre is an audiology

## Earbus Treats Aborigines In Rural Regions of Western Australia

### (Continued)

clinic being established at the Central Hospital attached to the College of Medicine in Malawi. The facility is near completion and scheduled to open next year. "This medical-school-based program will train village health workers [as ENT surgeons] to identify and refer people with ear disease and hearing problems."

"This clinic will be headed by a new graduate who is returning to his country as a Malawian ENT surgeon." A second Malawian clinic is also being started in this region.

The first Malawi project is especially exciting because the Centre is slated to be the base for expansion of ENT services throughout the country as part of a "national plan for ear disease and deafness."

"In Malawi, the backbone health care personnel are the medical assistants – the equivalent of the Asian 'Barefoot Doctors.'" Malawi has a program for training these medical assistants to become ENT clinical officers.

"To date, there have been 30 graduates from the program who have been deployed to various hospitals throughout the country to provide ENT services."



Paul Higginbotham and NP Stacy

There is a real need for audiological and ENT services within long stretches of poor villages in Western Australia. "Wherever you find poverty, you find middle ear disease, pretty much," says Paul Higginbotham, CEO of the Earbus foundation of Western Australia, headquartered in Perth. He and Lara Shur, the team's audiologist and speech pathologist, discuss the non-profit's mission.

The Earbus partners with Aboriginal Medical Services in Kalgoorlie, Port Hedland, Maya and Bega Gambirringu to provide mobile clinics and medication.

"From north to south are a couple of thousand miles, and from east to west are about 1,500 miles. It's a huge area - the heart of Western Europe, so getting services into these regions is a real challenge," Explains Higginbotham.

The outreach is in the process of receiving a state-funded, hospital-based contract to screen infants in remote areas of Western Australia. "Every neonate is now screened at

birth [to determine] if they have a hearing loss," explains Higginbotham. "This is done in the UK, Europe, New Zealand, Canada, and the US - all babies in the Western World." The first program of its kind originated in Colorado.

Aboriginal communities suffer from middle-ear disease "at ten times the rate of non-aboriginal Australians," says Shur. Poverty and lack of access to simple necessities influence their living conditions and impact their health, such as "access to clean water, 16 children in one home, excluding a number of adults," and access to medical care.

The community needs education regarding prevention of middle-ear disease, including the importance of breastfeeding to counteract newborn infections.

"On average, aboriginal children have middle ear disease for 32 months of the first five years of life," explains Higginbotham. "It can impact brain and early childhood development. The children are already failing by the time they start school."

Hearing loss not only devastates speech and language development in early childhood but also impacts "social play, self regulation, even issues like balance and coordination, and sensory integration," explains Higginbotham.



## Advisors

In addition to lay advocates, SMED has 45 advisors from 32 countries who “are worldwide experts in middle-ear disease, and who have been my colleagues over the years,” said Dr. Charles Bluestone. “There is a very strong heritage that I am very proud to say that I had some influence and guidance in their missions.”

One such SMED advisor is Dr. Leslie Salkeld, who has been treating the Maori. “They are the indigenous population of New Zealand and very prone to middle-ear disease from infancy on to adulthood,” said Dr. Bluestone.

For the past 35 years, SMED advisor and long-time ally, Dr. Harvey Coates, has been spearheading medical treatment for the indigenous Aborigine population of Australia. “Almost everybody had ear disease when they were a kid, and they still have it as adults,” said Dr. Bluestone. “It can be very lethal if it’s not handled properly.”

“Dr. Bluestone’s guidance and encouragement led to my colleagues and me publishing images of the first human biofilm from a child with chronic suppurative otitis media in his text book in the early 2000s,” said Dr. Coates.

“We were delighted to have Dr. Bluestone as our guest speaker for our Otitis Media meeting in Perth in 1983,” said Dr. Coates. “Over the years, we met at various conferences and venues as far apart as Thailand,

Aspen and the extraordinary World Otitis Media meeting in Helsinki.”

Another SMED advisor, Dr. Richard Rosenfeld, who practices pediatric otolaryngology in New York, was a fellow of Dr. Bluestone’s for two years when he first headed up the Department of Otolaryngology at the Children’s Hospital of Pittsburgh in 1975.

The New York doctor has developed guidelines, and continues to spearhead guidelines for diagnosis and management of middle-ear disease in the US, according to Dr. Bluestone. The guidelines from the US and other countries appear on the SMED website, and are “key to getting people to be aware of otitis media, and how to make a diagnosis and treat it.”

The Medical Director for SMED is Dr. Margaretha Casselbrant. “She was my successor to the chair of Pediatric Otolaryngology at the Children’s Hospital in Pittsburgh,” said Dr. Bluestone. Recently, Dr. Casselbrant became the secretary/treasurer of the new International Society of Otitis Media. ISOM professionals pay dues every year and meet every four years in the United States and every four years internationally.

The major difference between the two organizations is that ISOM is a professional society and SMED is a lay organization with a focus on global communities.

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“In one remote community [that we encountered], 86 percent of the children could not pass the hearing screening due to otitis media,” says Higginbotham, comparing the World Health Organization (WHO) benchmark [desire] for otitis media to be at four percent of the population.

Genetics play a role in the disease, for both aboriginal and non-aboriginal residents, adds Shur.

The bus is funded by government grants and carries a team that includes an audiologist, ENT specialist, nurse practitioner and general practitioner.

The crew offers education and training, medication, surgery lifts, postoperative follow-up, hearing screenings, ear irrigation and wax removal to prevent discharge, Betadine treatment for infected ears, as well as general medical care.

“The [children] often have head lice, visual issues, and undiagnosed genetic conditions,” he explains. “We are

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treating the whole child as well as the ear."

The Earbus program was started in February 2014, by ENT specialist and SMED advisor, Dr. Harvey Coates. It was modeled after a similar service operating in New Zealand during the 1980s.

The mobile clinic visits small towns and communities in the region of Goldfields-Esperance, 370 miles east of Perth, on a monthly basis.

"The aboriginal communities are transient," says Higginbotham. "They disappear 600 miles away in another location."

Once children reach their late teens, many of them have no eardrums left, often due to ear infections with discharge.

"So, it is very important that we get their hearing back as close to normal as we can as quickly as we can," says Higginbotham.

"Otitis media is a nasty disease but in and of itself just a disease, except for its impact on development," says Higginbotham. "If we can restore children to their full potential to learn and succeed at school, then we've beat the disease."

The goal is to educate families, teachers and childcare workers to clear up cultural passivity.

"We've seen a tolerance of ear disease being a natural part of childhood, and something you can't really do much about," says Higginbotham.

"We're trying to be a catalyst for



Dr. Harvey Coates with audiologist Lara Shur

change," Higginbotham explains. "To build capacity in aboriginal health services and communities to take over - so educating elders, teachers and children to understand the disease, and to play a proactive role in managing it."

Educators are trained to identify children who need extra help. "If they don't realize that the children have a hearing loss, they mistake behaviors for noncooperation, disobedience and disruptiveness," he says.

Some children are learning to advocate for themselves, by questioning their need for help.

Pilbara, 1000 miles north of Perth, is a remote community with aboriginal settlements. "They don't get much by way of health services," says Higginbotham. "For some children, it's their first visit for a very long time."

The team uses green pus, which can rupture ear drums, as a performance indicator.

"For example, 40 children had green pus in their ear, and now we have two ears that are discharging," explains Shur.

"I would be confident to say that in 12 months, we've reduced the number of discharging ears from otitis media to about 90 percent," states Higginbotham.

Otitis media is more far-reaching than health, and becomes a social and societal problem, impacting the cycle of poverty.

"Aboriginal people are massively over-represented in the justice system," says Paul. "Seventy-five percent of juveniles in detention in Western Australia are aboriginal, and they represent 2.5 percent of the population."

"If we can't give these children enough hearing to succeed at school, we're losing a generation of children, and that affects all of us," he says.



Dr. Karen in Strelley

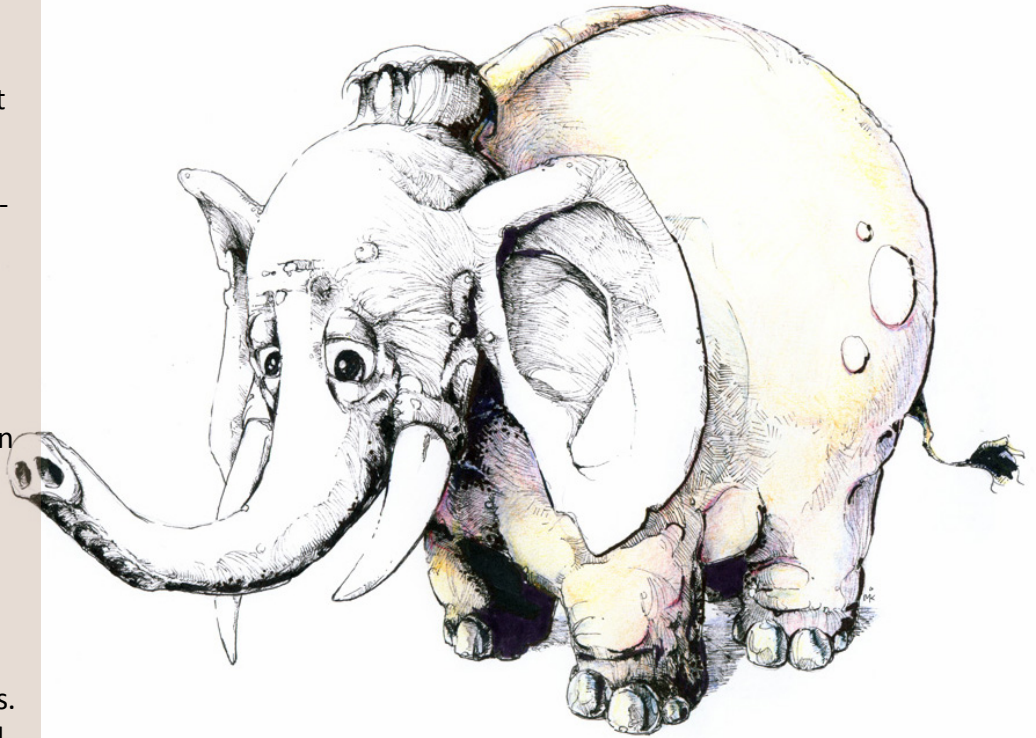
SMED is looking for ways to spread the word to mothers of young children about diagnosis, treatment and prevention of otitis media.

"Their baby is going to have middle-ear disease at least once before it turns five years of age," says Dr. Bluestone. "No question, every study shows that breastfeeding, especially into the sixth month, is very successful in reducing and even preventing otitis media," says Dr. Bluestone.

"We want to get mothers who are thinking about breastfeeding, 'should I do it, or should I not?' be advised about otitis media," he says. "Some have no time for it. It's hard for them to pump their milk at work."

Some babies get otitis media multiple times in the first year of life, due to an immature Eustachian tube and underdeveloped immunity. "We should be born at 21 months of age, not at nine months. It's 12 months too early."

"Humans are the only mammals that are habitually bipedal," explains Dr. Bluestone. "We freed up our hands to make tools and weapons, which has certain advantages, but there are distinct disadvantages, such as spinal, hip, knee and ankle problems. Very important, being bipedal and upright has resulted in the human female having a very narrow pelvis that results in their relatively big babies being born-too-soon."



## Babies Born Too Soon

"Otitis Media: The Case for Human Evolution in its Pathogenesis":  
<https://societyformiddleearisease.org/middleearvideo/>

"The Eustachian tube, which supplies air from the environment to the back of the nose and then to the middle-ear, is too short, and floppy in young infants," he says. "Bacteria and viruses in the nose and behind the nose gets into the middle-ear, and causes infection. The short tube is closer to the outside environment" and causes these organisms to enter the middle ear and mastoid.

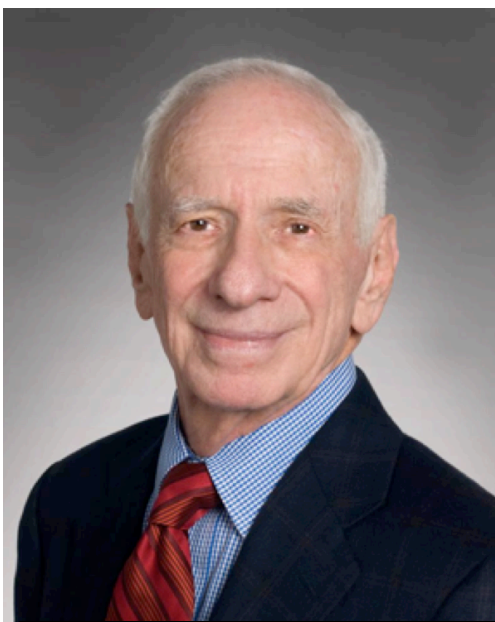
Dr. Bluestone studied the differences between humans and other mammals while on safari in East Africa.

"It triggered something in him

about how animals were born relatively mature and most likely without middle-ear disease since if they had otitis media and its associated hearing loss, they would die. They would be too vulnerable with poor hearing to let them know that predators were coming," says Maria Bluestone, who has collaborated with her father-in-law on many publishing projects.

"Also, if you're impaired at birth and unable to join the herd when you're in the jungles of Africa, you're eaten," explains Dr. Bluestone.





*"Children and adults die from complications of otitis media, mainly mastoid infections, because they don't get treated."*

*-Dr. Charles Bluestone*

## SMED Blends With Eye and Ear Foundation

"I am very pleased that the Society for Middle-Ear Disease has gotten off to a successful start," says Dr. Charles Bluestone about the recent transition from the Children's Hospital of Pittsburgh Foundation to the Eye and Ear Foundation of Pittsburgh. <http://eyeandear.org>

"SMED is excited about joining forces with the Eye and Ear Foundation," he says. "It is a logical partnership because the Eye and Ear Foundation specializes in sensorineural hearing loss located in the inner ear and central nervous system, but they have never had a

## SMED Mission - Family Advocacy

The Society for Middle-Ear Disease (SMED) is an international, non-profit foundation with a patient-centered focus that is responsive to needs and respectful of values, allowing patients to take charge by making care decisions.

The non-profit is advocating for mothers of young children who want to prevent ear infections by explaining the complications and potential for hearing loss, and partnering with community organizations to reach families.

The SMED website is expanding to include practical information and educational videos that explain the best treatment methods for middle-ear disease. Our "Parent Update" blog:

<https://societyformiddleearisease.org/category/blog/parent-updates/>

Posts weekly tips and information for parents of infants and young children.

On the website in the professional section, physicians are provided with guidelines and advice for diagnosing and treating otitis media, as well as updates on the latest research and clinical findings of ear, nose and throat experts internationally.

Advisors may e-mail [cynthia.writer@comcast.net](mailto:cynthia.writer@comcast.net) to let us know more about you to be posted our website blog, "Advisor Outreach":

<https://societyformiddleearisease.org/category/blog/advisor-updates/>

That feeds into our social networking sites, including Twitter, Facebook, LinkedIn and our Google Page.

And lastly, to address a shortage of ENT specialists internationally, SMED is looking for ways to establish and fund a fellowship program in Pittsburgh for visiting scholars to train in pediatric otolaryngology.

Give to SMED: <https://eyeandear.thankyou4caring.org/DonateNow>

program for otitis media," he explains. "Yet, it is the most common disease in infants and children, and not uncommon in adults." The Eye and Ear Foundation has had a very robust program for vision for many years.

Gayle Tissue, a founding member of the SMED Board, initiated the

change. "While I did come up with the idea of moving SMED over to the Eye and Ear Institute, it was Lawton Snyder [Executive Director of Development for the Eye and Ear Foundation] who shepherded the idea for the Eye and Ear Board," she stated in a recent e-mail. "A clear reason for moving it was to get it to an

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<https://societyformiddleearisease.org>

organization that focuses on ear [and eye] problems exclusively. If that's what you do all day, then the topic is important to you, and you will do the best job possible."

SMED was founded four years ago when Dr. Bluestone, "realized we had no advocacy group [for middle-ear disease] in the world that is a community-managed society like there is for cancer, diabetes, sickle cell [anemia], and atherosclerosis."

On its website, SMED is providing medical guidelines for ENTs, pediatricians and family physicians around the world. The non-profit is also a web resource for patients and parents of young children who want to prevent and manage middle-ear disease.

A long-term mission for SMED is to raise money for a program to provide advanced training for otolaryngologists in middle-ear and mastoid surgery in developing nations, or the "battlefield of the world," as Dr. Bluestone defines it. "They have not, in my estimate, trained enough ear surgeons to treat middle-ear and mastoid disease that has progressed into a potential lethal condition, like into the brain. It is estimated that 20,000 individuals die each year from complications of ear disease, primarily in developing countries."

As funding occurs, ENT surgeons from countries such as in Africa

and Asia, who do not have advanced training in complications of otitis media, would be offered training in the Department of Pediatric Otolaryngology, Children's Hospital of Pittsburgh of UPMC, Pennsylvania.

"It is not only the most common disease in childhood, but those are the complications that are managed by otologists and pediatric otolaryngologists."

"We want to solicit the money to set up programs in their countries to train these fellows in middle-ear disease and its complications, so we need donations."

The Eye and Ear Foundation is helping with fundraising for SMED. The hope is that otitis media will be ameliorated and complications prevented in these countries.

Middle-ear disease often goes untreated in Africa and Asia. "Children and adults die from complications of otitis media and mastoid infections, because they don't get treated. It moves onto a chronic phase that can result in a mastoid infection that spreads to the brain. They can die of a brain abscess and meningitis," said Dr. Bluestone.

"Other complications, such as a cyst, or cholesteatoma, in the middle ear and mastoid also can be deadly."

## SMED Founder Shapes Field of Otolaryngology

Dr. Charles Bluestone founded SMED in 2012. He organized two groups of people for the SMED Board. Originally, the intention was to have one group, the Advocates, consisting of his former patients and people with a history of middle-ear disease. But a second group, the Advisors, brought together 42 well-known ENTs and pediatricians Dr. Bluestone has worked with in the US and around the world.

Dr. Bluestone's family shaped him. "He had two siblings, and the three of them were in wildly different fields - medicine, art, and aeronautical engineering," says Maria Bluestone, his daughter-in-law. "His parents always encouraged all of them. There was no 'best' career path." His wife, Patsy, has supported him throughout his career. Maria has been an invaluable editor of his manuscripts.

The field of ear, nose and throat had an early imprint on Dr. Bluestone, from his late artist sister's husband, Dr. Robert Lewy, a laryngologist, and his father, the late Dr. Alfred Lewy, also an ENT doctor. Both were well-known otolaryngologists in Chicago. Dr. Robert Lewy would bring nine-year-old Charley into the operating room to observe procedures.

Educated at the University of Pittsburgh Medical School and trained in ENT at the University of Illinois in Chicago, Dr. Bluestone then did his two-year military service as an ENT surgeon in the Air Force in San Antonio, Texas.



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In 1972, Dr. Bluestone, with his family, moved to Boston to head up the Boston City Hospital's ENT department and teach at Tuft Medical School, as well as Boston University and Harvard Medical Schools. "I was one of only four or five Pediatric ENT specialists in the US back then, and now there are over 500," he says.

Dr. Bluestone trained 60 fellows, postdoctoral students in Pediatric Otolaryngology as part of the Children's Hospital of Pittsburgh of UPMC and the University of Pittsburgh Medical School. His influence is worldwide as seen in the 2004 "Festschrift" honoring his career, and where he thanked his trainees.

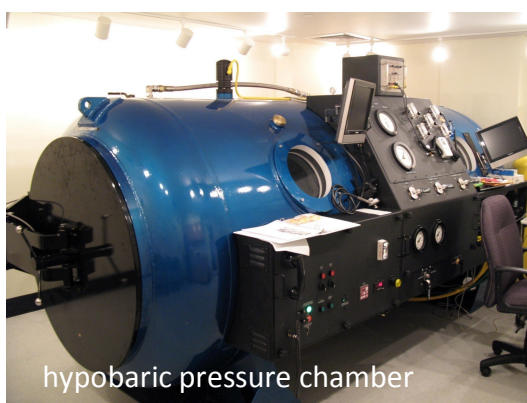
"He's given a lot of people opportunities. These fellows have turned those opportunities into career paths for themselves - and me included," says daughter-in-law, Maria Bluestone. "His past experience is that you get more when you share, and when you're open. He's generous with his knowledge, and very willing to give people a try."

Nancy Snyderman, a recently retired NBC medical correspondent, was a resident in Pediatrics at the University of Pittsburgh, and also a resident otolaryngologist during Dr. Bluestone's tenure.

"I was involved in Nancy Snyderman's training, but she didn't go into pediatric otolaryngology, she went into cancer surgery," he explains. She has been

instrumental in promoting the Pittsburgh Otolaryngology Department and SMED, and speaking at events.

In 1980, Dr. Bluestone founded the NIH-funded Otitis Media Research Center (OMRC) research center. Dr. William Doyle is the current director with J. Douglas Swarts, Ph.D., running the unique pressure chamber to test Eustachian tube function. Dr.



hypobaric pressure chamber

Cuneyt Alper, Professor of Otolaryngology, participates in research and treatment for subjects at the clinic. Over the years, since the founding of the OMRC, Dr. Bluestone received two \$5 million NIH (National Institute of Health) grants for five years to fund his research.

Dr. Bluestone is still co-investigator on a \$6 million NIH research grant funded for five years. The research is conducted out of the Otitis Media Research Center and Clinic (OMRCC) located at the Children's Hospital of Pittsburgh of UPMC. Clinical trials welcome patients into a hypobaric pressure chamber to study middle-ear pathology and the impact of swallowing and certain muscles on ear pressure. "This is

the only pressure chamber that is available to lay individuals in the area," Dr. Bluestone says.

Dr. Bluestone and Dr. Sylvan Stool participated in creating the Children's Hospital of Pittsburgh's Pediatric Otolaryngology Department in 1975. With the late Dr. Sylvan Stool, Dr. Bluestone developed the field of pediatric otolaryngology and wrote five seminal textbooks used by ENTs around the world. Dr. Stool also did extensive work with guidelines. "Our two-volume textbook on pediatric otolaryngology is the only one in the world."

Dr. Bluestone, along with his colleague, Dr. Jack Paradise, conducted NIH-funded clinical trials that have changed the field of otolaryngology with fewer tonsillectomies being performed for recurrent infections.

Currently, Dr. Bluestone is on the honorary faculty at the Children's Hospital of Pittsburgh of UPMC, and a Distinguished Professor Emeritus of Otolaryngology in the School of Medicine, University of Pittsburgh.

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