



Your Voice

Newsletter of the Institute of Laryngology and Voice Restoration

MISSION

The Institute of Laryngology and Voice Restoration (ILVR) is a non-profit organization seeking to advance laryngology and voice restoration through innovative basic and transitional research, education and outreach programs.

ILVR is an independent 501(c)(3) organization that works in cooperation with Massachusetts General Hospital, Harvard University, Massachusetts Institute of Technology and other institutions.

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INSIDE

Updates on clinical programs, education activities and research initiatives

New laser technologies advancing the treatment of laryngeal diseases

The Voice Restoration Research program: Seeking a cure for vocal cord scarring

Personal profile: Living with laryngeal papillomatosis

Harvard Professorship in Laryngeal Surgery

Institute of Laryngology and Voice Restoration

Supporting Clinical Programs, Education and Research in Boston and around the world

Since its inception as a federal non-profit organization, the Institute of Laryngology and Voice Restoration (ILVR) has provided support for a wide variety of unique clinical, research and educational initiatives.

CLINICAL PROGRAMS

MGH Voice Center

In July 2004 the ILVR and the Eugene B. Casey Foundation provided major support

to the Department of Surgery of the Massachusetts General Hospital (MGH) to build what is likely the most comprehensive facility in the world for managing laryngeal and voice disorders.

The MGH Center for Laryngeal Surgery and Voice Rehabilitation (AKA: MGH Voice Center) occupies approximately 12,000 square feet on the top floor of One Bowdoin Square in Boston, where unique state-of-

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Rock's Best Laser Light Show is in Steven Tyler's Throat

Reprinted with permission from *The Wall Street Journal*

By Zachary M. Seward
 Wednesday, August 16, 2006

Boston – STEVEN TYLER, the rock star and lead singer for Aerosmith, lay on an operating table at Massachusetts General Hospital in March, a thin laser snaking through

his iconic mouth and down into his legendary pipes.

Nearly six months into a North American tour, a popped blood vessel on Mr. Tyler's right vocal cord had reduced his singing voice to a hoarse shrill and forced Aerosmith to cancel all 20 of its remaining concerts. The injury was a potential disaster for Mr. Tyler, whose hot-blooded, high-pitched tones have defined his 33-year career. Even the slightest

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Dr. Robert Hillman, Co-Director and Research Director of the MGH Voice Center

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the-art facilities have been configured and equipped to provide the latest in clinical care to patients, and to advance the research and educational missions of the Center. MGH Voice Center is under the direction of Steven M. Zeitels, MD and Robert Hillman, PhD, Co-Director and Research Director.

At the Center, laryngeal surgeons (laryngologists), speech language pathologists, and voice scientists work together as a team to provide care to patients with voice disorders (including video-endoscopy and stroboscopy, electromyography), medical and surgical management, and voice therapy services.

The team is internationally recognized for their special expertise in managing disorders for “professional voice users.”

The team at the Center is internationally recognized for their special expertise in

managing disorders for “professional voice users” (e.g., singers, actors, clergy, teachers, lawyers), laryngeal cancer, and vocal paralysis. They provide comprehensive voice rehabilitation to laryngectomy patients including tracheo-esophageal puncture prosthetics.

The MGH Voice Center has several grants from the National Institutes of Health and collaborates on research projects with Massachusetts Institute of Technology (MIT) and the MGH Wellman Lab. Research areas include voice restoration; vocal cord scarring; vocal rejuvenation; novel laser treatment paradigms for benign and malignant disease; and development of a portable voice monitor with biofeedback for both diagnosis and treatment of voice disorders.

EDUCATION

Academic Programs

The ILVR endows yearly lectureships and academic panels at the annual meeting of the American Broncho-Esophagological Association (ABEA). The ABEA is a unique surgical society that was instituted about 90 years ago to advance the study and

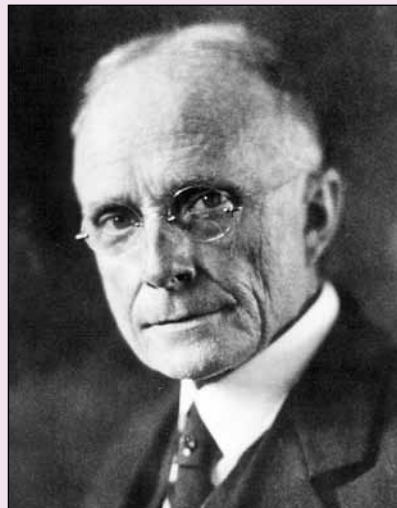
American Broncho-Esophagological Association

ILVR President John Ward delivers the Chevalier Jackson Lecture

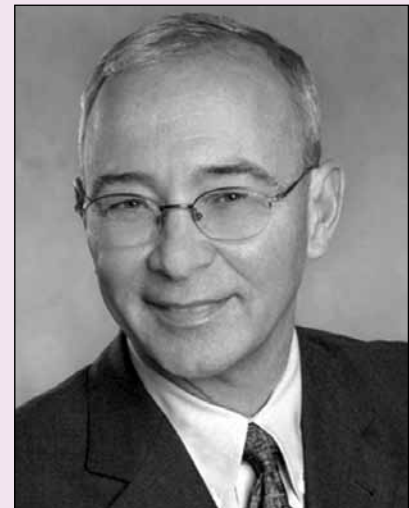
John Ward, PhD, the ILVR Board President, delivered the Chevalier Jackson Lecture for the 85th annual meeting of the American Broncho-Esophagological Association (ABEA). Dr. Ward discussed the complex nature of undergoing larynx cancer treatment from the perspective of a patient.

Dr. Steven Zeitels, who served as the president of the ABEA in 2005, followed Dr. Ward as the 86th annual Jackson Lecturer. His lecture was, “Concepts and Culture of Innovation: Lessons in Laryngeal Surgery.”

Given the commitment of the ABEA to excellence in research and education, the ILVR has endowed an annual academic initiative at the ABEA meeting to be comprised of a visiting lecturer and/or an educational panel discussion.



Dr. Chevalier Jackson (1865-1958) was one of the great leaders and innovators in laryngeal surgery in the first half of the 20th century.



Dr. John Ward, (ILVR Board President) sustained two vocal cord cancers and has now been cured of the disease from unique laser treatment designed by the MGH team.

treatment of diseases of the upper airway and food passages.

The ILVR supported a symposium on laryngeal imaging at the annual meeting of the American Speech and Hearing Association in Miami in November 2006.

Student Scholarships

During the past year, the ILVR has funded a number of research and education programs including student scholarships for the New England Conservatory and the New England Chapter of the National Association of Teachers of Singing.

Harvard Medical School Continuing Education Courses

The ILVR works with Harvard Medical School (HMS) and the MGH to present Continuing Medical Education courses. The first was a comprehensive two-day course providing a state-of-the-art update on Laryngeal Surgery and Voice Rehabilitation. The second course, “Office-Based Laryngeal Surgery” was the first of its kind and presented the pioneering work in laser surgery of the MGH researchers to attendees from around the world.



Medical professionals from across the world attend the ILVR supported Harvard-MGH Continuing Medical Education Course “Office-Based Laser Laryngeal Surgery.”

RESEARCH

A majority of laryngeal and voice problems are solvable in our lifetime. The past decade has demonstrated that with dedicated research teams and sufficient funding, remarkable advancements can be made in a short time period. Laryngeal and voice research is achieving outstanding successes and it is critical for the momentum to continue given the importance of voice in our communication-based society.

Voice Restoration Research Program

The ILVR is providing significant support for the MGH Voice Center’s main research focus, the Voice Restoration Program, which is aimed at developing methods for restoring vibration to scarred vocal cords (see related article on page 6).

Vocal fold scarring is the leading cause of voice loss. With support from the ILVR, researchers at the MGH Voice Center have teamed up with other scientists from MGH, Harvard Medical School (HMS) and

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Dimitri Papaioanu Visiting Professor

Personal and academic tribute to the memory of an educator and father

In furtherance of its educational mission, the ILVR co-sponsored with the Department of Surgery at Massachusetts General Hospital the Dimitri Papaioanu Visiting Professorship. The lecture “Optimizing Results in Phonosurgery” was presented by Dr. Charles N. Ford, Professor and Chairman of the Department of Otolaryngology – Head and Neck Surgery at the University of Wisconsin, Madison.



A leader in the field of Laryngology, Dr. Charles Ford (left) presents to physicians, health professionals and educators in the historic Ether Dome of the Bulfinch Building on the MGH campus.



Theopula Papaioanu, with sons Athanassios and Paki, traveled from Greece for the tribute to her late husband.

Eugene B. Casey Professorship in Laryngeal Surgery at Harvard Medical School

One of the most important contributions to the field of laryngology the ILVR has made was to establish and endow the Eugene B. Casey Professorship in Laryngeal Surgery at Harvard Medical School, in the Department of Surgery of the Massachusetts General Hospital. This was made possible through the gracious and generous philanthropy of the Eugene B. Casey Foundation of Gaithersburg, Maryland.



(l-r) Joseph Martin, MD, Dean of Harvard Medical School, presents the Harvard Bowl to Dr. D Shinkle representing the Eugene B. Casey Foundation, with incumbent chair, Steven M. Zeitels, MD.

In establishing this professorship, the ILVR has ensured that the highest quality clinical care in Laryngeal Surgery will be maintained. The professorship also supports advancements in Laryngology through novel and enterprising research programs. In recognition of Betty Brown Casey's commitment to the welfare of children, innovative approaches to pediatric voice loss have been instituted.

The first incumbent to the Casey Professorship is Steven M. Zeitels, M.D. Dr. Zeitels is the Director of the Massachusetts General Hospital's Center for Laryngeal Surgery and Voice Rehabilitation. He is an international leader in the field of phonosurgery and is known for the passion and vision he brings to his work. □



Andrew L. Warshaw, MD, Surgeon-in-Chief of the Massachusetts General Hospital and Steven M. Zeitels, MD.

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MIT in a major effort to solve this problem.

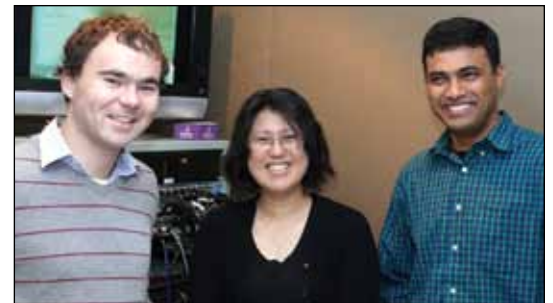
The participation/collaboration of outside research groups in this work is made possible by the ILVR support that they receive. A new basic science laboratory will soon be constructed at the MGH to accelerate progress on this initiative.

Research Grants

Massachusetts Institute of Technology (MIT)

ILVR is providing significant funding to scientists at MIT in the laboratories of Dr. Robert Langer where the majority of the work to develop bio-implants for repairing damaged (scarred) vocal cords is taking place. Dr. Langer is one of the world's preeminent experts in the development of bio-materials for medical applications, with his group having already patented hundreds of their innovations. Funding for the Langer Laboratory not only covers expenses related to experiments, but also provides support for post-doctoral research fellows to help carry out the work.

The current post-doctoral fellow, Dr. Sandeep Karajanagi, is working under the direction of Dr. Hyuongshin Park on an approach that combines synthetic materials with human tissue. ILVR funding is also supporting Conor Walsh, a PhD student at MIT in mechanical engineering, to work on the development of new methods for assessing the bio-mechanical properties that are responsible for vocal-cord vibration. This work is expected to improve the assessment of both vocal cord damage and the effectiveness of new bio-implants in repairing such damage.



Conor Walsh, Hyuongshin Park, and Sandeep Karajanagi

University of South Carolina (USC)

ILVR provided a research grant to support Dr. Dimitar Deliyski's work at the USC for developing new ultra high-speed methods for imaging vocal cord vibration in the clinic.

Dr. Deliyski's work will ultimately enable voice specialists to obtain much more detailed information about how the vocal cords are functioning, which will enhance our understanding and knowledge of human voice production. This will lead to improvements in the diagnosis and treatment of human hoarseness. □

National Association of Teachers of Singing

The ILVR supported an educational day for 100 New England members of the National Association of Teachers of Singing (NATS). The event was comprised of a series of lectures followed by a tour of the new MGH Center for Laryngeal Surgery along with displays of research initiatives.

The ILVR also funded a student to represent the New England Chapter in the national competition for NATS. Michelle Trainor of Cumberland, Rhode Island received the award, placing sixth in the nation. □



Voice student Michelle Trainor, pictured with her teacher Anna Gabrieli, attended the Minneapolis-based national competition.

American Speech-Language-Hearing Association Workshop

The ILVR provided funding to help the American Speech-Language-Hearing Association present an advanced comprehensive workshop entitled “*Laryngeal Imaging: Seeing is Believing*” in association with its annual international convention, held November 2006 in Miami, Florida.

The workshop is focused on the current uses and future applications of laryngeal imaging tools in assessing voice, and was primarily directed at updating the knowledge and skills of clinical speech-language pathologists who evaluate and provide voice therapy to patients with vocal disorders. □

Harvard Continuing Medical Education

ILVR sponsors one-of-a-kind courses to bring the latest advances in treatment and technology to medical professionals from around the world.

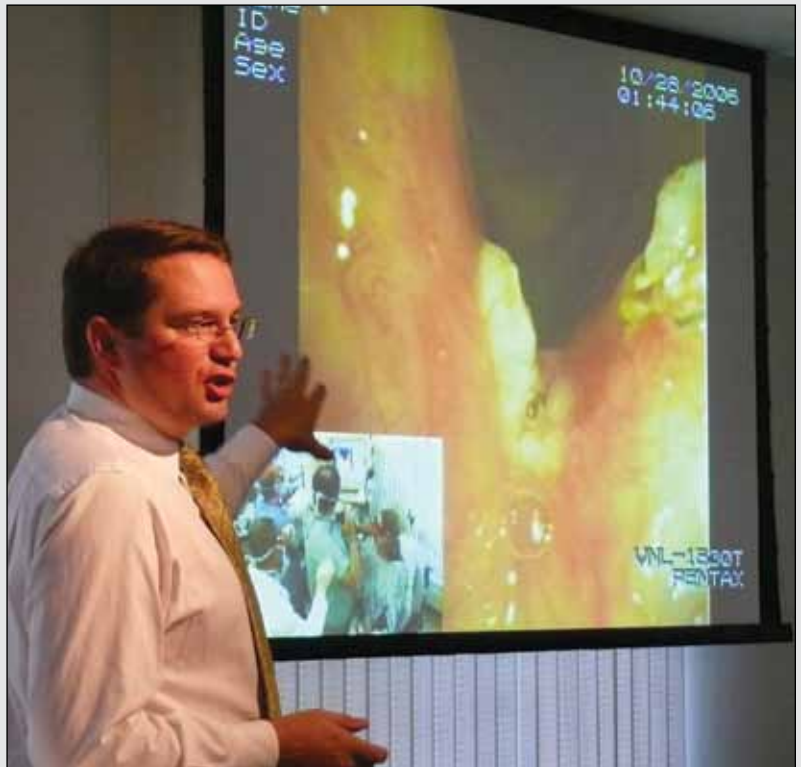
Office-Based Laryngeal Surgery: 2006

In 2006, ILVR and Harvard Medical School cosponsored the first course in office-based laryngeal laser surgery, co-directed by Dr. James Burns and Dr. Zeitels. Dr. Zeitels and his team created this new surgical paradigm five years ago in collaboration with Rox Anderson, MD, Director of the MGH Wellman Center of Photomedicine. Surgeons from seven countries and 15 states attended the unique course so that they could institute the new style of surgery in their respective institutions.

Laryngeal Surgery and Voice Disorders: 2005

In 2005, Harvard Medical School, in conjunction with the Departments of Surgery and Speech Pathology at MGH and ILVR, sponsored a two-day course for physicians, surgeons, speech pathologists and voice teachers to provide them with a state of the art update in the field.

Course Directors were Drs. Zeitels and Hillman, and presentations were by noted leaders from Harvard and experts from other institutions in the United States and Canada. They focused on new approaches and trends as well as highlighted future directions in Laryngeal Surgery and Voice Rehabilitation. □



Dr. James Burns teaches an audience of surgeons at the MGH Voice Center during a live laryngeal laser surgical procedure being done in the clinic facility down the hall.

Finding a cure for VOCAL CORD SCARRING

A giant step towards eliminating hoarseness as a medical condition

The ILVR is the major source of support for The Voice Restoration Program, a multidisciplinary research effort focused on finding cures for vocal cord scarring.

Vocal cord scarring: the leading cause of voice disorders

The leading cause of voice disorders is the loss of pliability in vocal cord tissue due to scarring. Scarring of vocal cords is caused by a variety of conditions including heavy voice use, aging, surgeries and other treatments involving the larynx (eg. radiation therapy for cancer), exposure to environmental irritants and congenital conditions.

Such scarring restricts or eliminates the vibration of vocal cord tissue that is essential for the production of human voice. ***There is currently no viable method for restoring pliability to scarred vocal-cord tissue.***

To solve this problem, researchers from the MGH Voice Center, under the direction of Dr. Steven Zeitels, teamed up with scientists from other departments at MGH, Harvard Medical School and Massachusetts

Institute of Technology (MIT) to launch a comprehensive multi-disciplinary research project.

Other major collaborators include Dr. Robert Langer and his tissue-engineering group at MIT, as well as Dr. Rox Anderson and his laser specialty group in the MGH Wellman Laboratory for Photomedicine.

Success will result in restoring voices to millions of people.

ILVR support for the program enabled the research team to attack the vocal-cord scarring problem at multiple levels.

Some members of the team are working on developing ***vocal cord bio-implants*** using a variety of natural and synthetic substances that are designed to replace lost pliability.

Other members are developing ***new surgical technologies*** that are needed to both prepare the vocal cord recipient site and

place the implant.

Still others are developing innovative approaches for assessing vocal cord function in terms of better imaging to differentiate healthy from scarred tissue, and ways to directly measure vocal cord biomechanical properties to assist implant design and testing.

Reversing long-term effects of aging

Success of the program will result in restoring voice to millions of people who are suffering from the problems associated with such voice loss including negative impacts on:

- everyday communication;
- psychological well-being;
- socio-economic function.

Solving the vocal fold scarring problem would include reversing the long-term effects of aging on voice, which is rapidly becoming more of an issue as individuals are living longer. □



Legendary singer/actress Julie Andrews (center)

with the investigators of the MGH Voice Restoration Research Program

(from left to right) Robert Hillman, PhD, Rox Anderson, MD, Steven Zeitels, MD (project leader),

Robert Langer, PhD, and James Kobler, PhD.

MGH Voice Center RESEARCH TEAM



Drs. Jim Kobler and James Heaton prepare to give a lecture in the Voice Center Conference Room.



Drs. Matthew Broadhurst and Gerardo Lopez-Guerra are shown with a new research surgical microscope.

Ongoing ILVR support has been instrumental in enabling Dr. Steven Zeitels (MGH Voice Center Director) and Dr. Robert Hillman (MGH Voice Center Co-Director and Research Director) to assemble a multidisciplinary group of investigators to focus on research to improve the prevention, diagnosis and treatment of larynx and voice disorders. This outstanding team currently includes three full-time doctoral-level research staff members, a research fellow, and one research technician.

James Kobler, PhD and James Heaton, PhD are the longest-standing members of the Center's research staff, having each worked with Drs. Zeitels and Hillman for over 10 years. Both have multifaceted backgrounds and expertise in a number of critical areas including neuroscience, vocal anatomy and physiology, tissue biology and instrumentation. Because of their versatility, Drs. Kobler and Heaton are involved in virtually all of the research projects carried

out at the Center. The newest member of the full-time research staff is Hyounghshin Park, PhD who has extensive training and expertise in the latest tissue engineering approaches. She is taking a leading role in the group's efforts to develop bio-implants for restoring function to damaged (scarred) vocal cords.

ILVR supports research fellowships

ILVR support has also made it possible for the Center to offer research fellowships to individuals that have already completed rigorous doctoral-level training in medicine or basic science. The fellowship program serves two main purposes. First, it extends and enhances the Center's research programs by providing a cadre of young and talented individuals to assist in the work being directed by the senior (full-time) research staff. Second, it provides the field with a supply of new investigators that have been

trained to pursue cutting-edge research that will expedite improvements in the clinical care of patients with larynx and voice disorders.

ILVR research fellowships have been awarded to two surgeons, Dr. Matthew Broadhurst (Brisbane, Australia) and Dr. Gerardo Lopez-Guerra (Barcelona, Spain), both of whom already completed residency training in Otolaryngology – Head and Neck Surgery (ear, nose and throat). These key positions have been invaluable for rapidly translating a variety of basic investigations to clinical application. These positions also facilitate the dissemination of new knowledge and training in the latest clinical and research techniques, which broaden constituencies nationally and internationally. Drs. Broadhurst and Lopez-Guerra have been working with a number of senior investigators at the MGH Voice Center on developing a variety of new surgical technologies. □

(Continued from page 1)

tweak in his throat – the stiffening of a vocal cord or a change in its vibration – could have forever altered the sound of “Walk This Way,” his signature tune.

But now, almost five months after his experimental surgery, he declares, “Oh, I’m back in action.” He proves it with a series of wild, cascading scales. “I can do the whole Janis Joplin thing,” he says.

Mr. Tyler had to rest his vocal cords after the surgery (“The hardest thing was not talking for three weeks,” he says), but he’s working full-time now. Aerosmith has been recording in the studio this month, and a new gig, “The Route of All Evil Tour” with Moetley Crue, began on September 5.

The National Institutes of Health estimates that 7.5 million Americans have trouble using their voice, with disorders ranging from spasms to tumors. Singers, who use their voices constantly with little rest, are at the highest risk.

How Mr. Tyler, 58, reacquired his voice, signature squawks and all, could have broad implications for professional singers silenced by vocal disorders. He was treated with a pulsed potassium-titanyl-phosphate (KTP) laser, the latest and most promising procedure to come out of Mass. General’s voice center.

Quick bursts of green laser light, lasting just 15 milliseconds, zapped Mr. Tyler’s broken blood vessel, sealing the vessel

without touching it.

The procedure is sounding a positive note for more successful and resilient recoveries from vocal disorders like Mr. Tyler’s. It has saved the voices of at least 14

other singers since 2005, including the opera star Carol Vaness.

A paper published last week by Steven M. Zeitels in the *Annals of Otolaryngology & Laryngology* (that would be ear, nose and

Laser Improves Treatment of Voice Disorders

Through ILVR support the research team at the MGH created a new laser-surgery paradigm for treating a number of vocal cord abnormalities.

This effort has resulted in a number of recent scientific publications* that establish the Pulsed-KTP laser as a key innovative technology for vocal cord surgery (phonosurgery). Phonosurgery refers to surgical procedures that maintain, restore, or enhance the human voice.

They have demonstrated that the Pulsed-KTP laser is safe and effective treatment for a number of benign and precancerous conditions. Preliminary data also shows that the KTP is a promising treatment option for early vocal cord cancer. This important and innovative work was covered by both national and international media including the *Wall Street Journal*, *London Sunday Times*, NBC, CBS, Fox, BBC and NPR.

**Annals of Otolaryngology, Rhinology, and Laryngology*: 115: 571-580 & 679-685



Dr. James Burns performing office-based laryngeal laser surgery in the outpatient treatment room in the MGH Voice Center.

throat) reports effective and “relatively safe” treatments in 39 singers, using the pulsed-KTP laser in some cases and an earlier incarnation, a yellow-light laser, in others.

“This is profoundly affecting the way we treat vocal disorders,” says Dr. Zeitels, who performed the surgery on Mr. Tyler.

A dermatologist at Mass. General, R. Rox Anderson, first developed the use of a pulsed laser for treating port-wine stains on baby skin. The laser heated the blood causing the stain without stiffening the delicate baby skin around it. Dr. Zeitels then applied the same concept to the vocal cords. Dr. Zeitels believes he's the only one using the pulsed-KTP laser on the vocal cords.

The National Institutes of Health estimates that 7.5 million Americans have trouble using their voice, with disorders ranging from spasms to tumors. Singers, who use their voices constantly with little rest, are at the highest risk. Greater touring demands have increasingly strained voice boxes in genres from opera to hip hop. And the belting, wailing, and screeching common among some singers, especially in hard rock and heavy metal, have led to still further woes.

Canceled appearances, delayed albums and shortened careers can frustrate both artists and their fans. Just this week, Mick Jagger was forced to cancel two Rolling Stones concerts in Spain after coming down with laryngitis, the band said.

“Just like athletes, singers need to have adequate rest,” says Jan Shapiro, chair of the voice department at Berklee College of Music in Boston. “Opera singers hitting high notes, even students practicing every day, that takes its toll. We see all sorts of voice problems and more now than ever.”

The offices of Mass. General's voice center, which has emerged as the nation's pioneer in the treatment of vocal disorders, are a testament to its range of high-profile patients. Signed head shots of such artists as Ozzie Osborne and Cher line the wall. A

photo features Sen. John F. Kerry, who lost his voice in losing the 2004 presidential election. Another shows a smiling Jack Welch, former chief executive of General Electric Co.

The dominant treatments for broken blood vessels in the larynx have traditionally been cauterization and removal with surgical tools. But both methods carry a high risk for altering the vocal cords, or vocal folds, as they are clinically known, by applying excess heat and leaving them stiff.

In Mr. Tyler's operation, the goal “was to get the vessel to seal without getting heat outside the vessel,” Dr. Zeitels says. “It's the heat outside the vessel that causes stiffening in the vocal folds.”

**That saved Prof. Ward's
voice, and he continues
to give lectures
and coach his child's
soccer team.**

Dr. Zeitels has used the laser to treat not only broken vessels, but also dilated veins, polyps and precancerous lesions known as dysplasia. The laser interrupts the blood supply that such disorders depend on to thrive. Many of the procedures can be performed in his office with just local anesthesia. The main risk is surgical error, since the treatment area is so small.

The treatment is not just for singers, either. “We get professors, CEOs, anyone who's using his voice all day without much rest for years and years,” says Robert E. Hillman, research director at the voice center. They have also begun using the pulsed-KTP laser on laryngeal cancer, helping to avoid radiation treatment or removal of the larynx.

John Ward, a business professor at Northwestern University, developed two cancers on his vocal cords, and many doctors said he would have to undergo radiation, which causes scarring and can only be used once.

But in three surgeries over several months, Dr. Zeitels was able to remove the larger tumor and eliminate the other by cutting off its blood supply with the yellow-light laser. That saved Prof. Ward's voice, and he continues to give lectures and coach his child's soccer team.

Almost four years later, Prof. Ward is considered cured and says in a raspy but healthy voice, “Dr. Zeitels not only saved my life but my career as well.” The experience led Prof. Ward to help form the Institute of Laryngology and Voice Restoration, which has raised more than \$5 million for the Mass. General voice center in three years.

That money, along with funding from the hospital itself, has allowed Dr. Zeitels to expand his practice into a full-blown research center, by far the world's largest in laryngeal surgery. The center is equipped with two advanced sound rooms, not unlike a recording studio, where doctors can make precise measurements of voice quality and lung pressure for comparison after treatment. A speech pathologist at the center, who is also a classical singer, outfitted her own examination room with a grand piano.

The center also provides continuing medical education classes for laryngologists and surgeons, sometimes presenting live demonstrations of the pulsed-KTP laser treatment.

One video shown to doctors features a view of Mr. Tyler's vocal cords, healed after surgery, as he sings Aerosmith's 1973 smash “Dream On” with his customary verve. The twin folds of mucous membrane vibrate violently over his larynx as Mr. Tyler hits the chorus, “*Sing with me, sing for the years...*” □

COURAGE ACROSS A LIFETIME: DEBRA'S STORY

Debra May's speaking voice is low and a little raspy. An elegant woman with a soft southern accent, she credits new office-based surgical procedures with saving her life.

When Debra was just a baby, her voice became increasingly weak. Concerned parents took her to a doctor who found Debra's declining voice was due to wart-like tumors, growing in size and number throughout her larynx, and obstructing her airway. Debra was diagnosed with juvenile papilloma, a disease caused by human papilloma virus (HPV).

At age three, the tumors were so widespread that doctors were concerned Debra's disease was life threatening. Surgeons cut an opening in her windpipe and inserted a metal tube into the opening (tracheotomy) bypassing tumors to allow air to get to her lungs.

From then on, Debra's voice was a whisper, and she breathed through a tube in her throat.

Debra's parents tried to give her as normal a childhood as possible, but there were challenges. Until technology produced an improved tracheostomy tube, Debra's mother had to remove and sterilize the metal tube daily. "This was difficult for both of us. My mother was not a nurse, but she was strong and got through it," remembers Debra.

Other children were confused by her uncommon disability, and she was limited physically. "I loved ballet lessons but others were uncomfortable with me dancing. I'm not sure if it was my general health, or the tracheotomy, but they made me stop."

And, the tumors were still growing, Debra underwent dozens of surgeries to remove them. "I wouldn't want any child to suffer the way I did," she says, "but I am grateful to my parents for all they did to help me."

Medical advancements allowed doctors to remove Debra's tracheostomy tube when she was 16.

"I had a voice for the first time that I could remember. Though it was not a pretty voice, I was elated to have it. Even if I wasn't



"The battle with papilloma has been a long one for me and many others. Dr. Zeitels is fighting this battle with us. We are finally able to receive the treatment that is less invasive and has a faster recovery rate so we may have more quality time with our families.

The treatment helps to eliminate the fears that the operating room has for a patient who cannot snap back as quickly as they once did.

What Dr. Zeitels has given me is hope for a longer and happier life, for which I will always be grateful. My wish is that many doctors will come and join this battle so that everyone who has this disease might benefit."

Debra May

healed, at least the last couple years of high school were more normal for me. I looked like other kids, and I could actually talk."

**"I wouldn't want
any child to suffer
the way I did."**

Debra also needed fewer surgeries, and over the next 17 years she led a nearly normal life, fell in love, and married Jonathan May. The couple wanted to start a family, but limited information was available to them about the risks of bearing children. She got pregnant, and Debra's tumors began to multiply at a dramatic and terrifying pace.

"It was very scary. I couldn't lay flat and still breathe so I had to sleep in a chair. We were concerned about our baby and its oxygen levels, but I couldn't have surgery because of the danger of going under anesthesia. It was a terrible time."

Debra and Jonathan finally welcomed a daughter, Ashley, but paid a hefty toll for their baby. Debra's disease, manageable for decades, flared up to an alarming level. She lost track of the exact number, but estimates she underwent 70+ surgeries.

The disease also prevented Debra and Jonathan from attempting to have another child. The risks to Debra's health were too high, and "It was more important that Ashley have a mother, than brothers or sisters," she explains.

The family had another pressing concern—Debra's health and spirit were weakening as she went under anesthesia every few weeks. "The number of procedures took a toll on me. I had pneumonia a couple of times, was exhausted, and couldn't catch my breath. It was scary. I didn't think Ashley would have a mother for much longer."

Then, Debra read an article about Dr. Steven Zeitels and his success with new office-based laser surgery offered at the MGH Voice Center in Boston. "I thought the procedures, which could be done without anesthesia, were too good to be true. I made an appointment immediately." The procedure removed the tumors in just a few minutes using a numbing gel to prevent pain.

Today, Debra and Jonathan regularly travel 400 miles to Boston for office-based surgeries. "I am just so grateful these procedures exist. I don't think that I'd be here if they didn't. For me and my family, it's a miracle." □

THANK YOU TO OUR DONORS

Since its inception in 2003, ILVR has grown to become one of the world's most significant contributors to the field of laryngology and voice restoration. More than nine million dollars donated by individuals and organizations has been used to support innovative research, education and clinical programs; substantially more funding has been earmarked for continued advancements. We could not achieve our goals without you.

Thank you.

Julie Andrews Fans Hold International Fundraiser for ILVR

An active member of an online fan club, Sladjana De Donna connects with hundreds of individuals across the globe who honor and cherish Julie Andrews' lifetime of artistic and charitable accomplishments. Sladjana and others in the group, ranging from age twelve to eighty, avidly follow Julie's career, and support her efforts to bring attention to the issues of voice treatment and restoration.

"She is a woman of great courage," explains Ms. De Donna, a New York resident and native of Yugoslavia. "Julie Andrews' collective work is without equal, but it is her heart and beautiful soul that inspire so many of us."

A vocal cord surgery in 1997 left Julie Andrews with serious vocal issues that gained worldwide attention and spurred many to question her ability to sing again.

In honor of Julie Andrews, Ms. De Donna organized a fundraiser for the ILVR to support research that is leading to solutions to complicated voice issues. The fundraiser "I'll Sing Once More" collected donations from 81 donors spanning the globe. □



From left: Dr. Steven Zeitels, Jennifer Mead and Sladjana De Donna of the Julie Andrews' Fan Forum, and Deborah Farrell Nelson, ILVR Director of Events and Communications.

The Institute of Laryngology and Voice Restoration (ILVR) is an independent, 501(c)(3) nonprofit corporation founded in 2003. The ILVR is dedicated to advancing laryngology and voice restoration through sponsoring innovative basic and translational research as well as promoting education and outreach programs.



PROGRAMS AND ACTIVITIES

- Fund on-going multidisciplinary research at world-class institutions leading to the initiation of clinical trials in laryngological surgical interventions in voice care and restoration.
- Sponsor fellowships for both clinical and research fellows in laryngology.
- Sponsor training for doctoral and postdoctoral scientists interested in voice-related sciences.
- Develop educational materials and programs for medical and health professionals and the general public in order to increase awareness and disseminate information about current developments in laryngology.

ILVR BOARD OF DIRECTORS

John L. Ward, PhD
PRESIDENT

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*Ways in which **YOU** can help* **END VOICE DISORDERS**

- ✓ Listen to the voice of your friends, colleagues and loved ones. If you know someone who seems hoarse for more than a few weeks, suggest they see a doctor.
 - ✓ Raise awareness among family and friends about the importance of laryngeal and voice disorders.
 - ✓ Share your story for a future publication.
 - ✓ Provide a donation to the ILVR's research, education and outreach programs. Your gift now will protect and restore the voices of tomorrow.
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FOR MORE INFORMATION CONTACT:

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