

WebWhispers Nu-Voice Club

The Internet Laryngectomee Support Group

New Members

The following new members joined WebWhispers in late July and in August. Please welcome them to our group.

Gary Bradshaw
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FIRST LARYNX TRANSPLANT PATIENT IN INDIANAPOLIS

By: Joe Casey

Tim Heidler, the recipient of a total larynx transplant last January, is alive and well and talking up a storm.

Tim was with us at the early August, 1998 Annual Meeting of the International Association of Laryngectomees (IAL) in Indianapolis. I had the opportunity to visit with him about his experiences and current status. Tim's voice is very close to normal in terms of strength, tone, inflection, pitch and the like. He still has a stoma which he occludes with his thumb while talking. There is slight hoarseness but not much. Tim reports that his voice continues to strengthen as time goes on and as he uses it more and more.

In a subsequent 75 minute presentation to IAL attendees, Dr. Marshall Strome who led the Cleveland Clinic's team in this extraordinary surgery stated that Tim would eventually make his own decision about closing the stoma. This would involve additional surgery, with its attendant risk of infection, and would result in what Dr. Strome termed an increase in the "breathiness" of Tim's voice.

Planning for the surgery took more than a year — but preparations have been under way for many years. Dr. Strome decided early in his career that he would perform successful larynx transplants. He left a successful career at Harvard Medical School to join the Cleveland Clinic which offered better and longer-term funding for the research required to make his vision a reality.

Dr. Strome and his team which includes microcardiovascular surgeons and particularly pharmacologists have performed a large number of larynx transplants on laboratory animals up to and including sheep. Particular emphasis has been and continues to be placed on regulating the dosages of the life-threatening drugs which are required to prevent the rejection of the transplanted organ by the body's immune system. At this point, the team has more larynx transplant experience than any other team in the world.

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Dr. Strome explained that his selection of Tim as the candidate for the first U.S. larynx transplant effort was based on:

- Age under 40;
- Excellent health other than massive damage to the larynx caused by a cable stretched across a road which caught him in the neck while he was riding his motorcycle to work;
- No malignancy of any type; and
- Good psychological balance.

Tim took two months to make his decision to proceed with the surgery in view of the fact that:

- The drugs required to prevent rejection of the transplanted organ are in fact life threatening, particularly if there are infection(s) which require other drugs for treatment and/or which weakened the body;
- There was a major risk of swallowing difficulties arising from the difficulty of connecting nerves which had been severed almost twenty years ago;
- There were potential thyroid problems; and
- He will be required to take suppressive drugs for the rest of his life.

The transplanted larynx was harvested from a man who died of a brain aneurysm but who had been otherwise healthy and free of both HIV and malignancy. The surgery was incredibly complex, both as to logistics (Dr. Strome and a microcardiovascular surgeon colleague personally harvested the organ and transported it by jet to Cleveland, arriving at 4:30 AM and then starting the long operation at 6:30 AM) and technique.

Amazingly, none of the many critical things which could have gone wrong did go wrong. There was no major infection and Tim's system tolerated the drug dosage well. However, he was monitored on a continual basis and there were various post-operative "emergency" situations which needed to be corrected. In addition, his saliva output was virtually eliminated by medication for the first three months until the swallowing reflex had been well established. If this had not been done, Tim would have choked on his own fluids.

New Members (Continued)

Jerry Hough

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WebWhispers Nu-Voice Club

New Members (Continued)

Sy Schreck

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We look forward to active discussions with all of our new WebWhispers members.

As reported in the press and on television, Tim spoke his first words, "Hello" and later "Hi, Mom" a few days after surgery and then was instructed to remain silent to allow stitches to heal. A few weeks later, he was allowed to speak his first complete sentence which was along the lines of "This is all that I had hoped it would be". Voice tests were then conducted on a regular basis. Listening to the audio tapes which Dr. Strome presented, one can hear the voice strengthen and the tone improve with each test.

Tim will be going in for his seven month checkup later in August. Assuming that all is well, Dr. Strome intends to continue to reduce his dosages of suppressive drugs.

Dr. Strome and his team will continue to work on making this procedure practical for all of actual and potential laryngectomees including those with cancer of the larynx. His near-term goal is to perform another twenty transplants over the next five to ten years and, at the same time, to demonstrate in laboratory animals that the drugs used to suppress the immune system do not cause a recurrence of cancer. At one point, he talked about "like-for-like" transplants which I took to mean replacing a diseased larynx at the time it had to be removed. Given the logistics involved, it is difficult to see how this would be possible because tumors will not wait until suitable donor organs are found and harvested.

One of the other problems facing prospective recipients will be cost. Dr. Strome mentioned that the Cleveland Clinic had "...funded the total \$200,000 cost of Tim Heidler's transplant". It sounded to me as though \$200,000 was unrealistically low. Among other things, Dr. Strome assigned his brightest Resident to do nothing else except monitor and care for Tim during an extended period following surgery (she will co-author the research paper once it is published). Whether or not \$200,000 is the right number, one has to question how many HMO's will authorize anything approaching this magnitude of payment for what they may well regard as a non-essential procedure?

Regardless of the technical and practical problems which are ahead, I would not bet against Dr. Strome and his team — or against those surgical teams who take his approach to new levels. His procedure will come too late for many of us — but will almost certainly be of benefit to younger laryngectomees to come.

Thank You!

To those members who have made a voluntary financial contribution in 1998 to help defray the costs of maintaining our WebWhispers site:

Wayne Baker

Walter Canney

Joe Casey

Jon Del Ben

Terry Duga

Bob Hoover and the Red Rose Nu Voice Club

Marianne Peereboom-Kooijman

Mary Alice Renison

Any member wishing to make a voluntary contribution for 1998 may do so by mailing it to:

David L. Helms
WebWhispers Nu-Voice Club
4101 NASA Road, Apt. 129
Seabrook, TX 77586-6210

Chat Room

We invite all members of WebWhispers to join our Chat Room on Sunday afternoons at 4:00 PM Eastern Time. Directions to the site are on our WebWhispers page.

First time users should go a little early and register (free of charge) with LiveUniverse. One pop-up screen will ask for your "Quote". Type in your name — it will show up in a panel to the left of the Chat Room summary and make it easier for others in the Chat Room to know who is talking.

To talk, type in your comments in the small box under the Chat Room summary and then press "Enter" (some of us took more than one session figuring out how to say something).

The Big Red "W" At Indy

Others at the recent IAL Annual Meeting in Indianapolis wondered about those who wore a large red "W" on their name tags. They soon learned that the "W" confirmed membership in the largest and fastest growing laryngectomy support group on the Internet and the largest club at the meeting.

Special thanks are due to **Terry Duga** for arranging a great dinner location at Boom Baby's for:

Allan Carson
Wayne Baker
Jon Bel Den
Mary Bergquist
Walter Canney
Joe and Kay Casey
Pati Cole
Terry Duga
Frank Farrell
Elizabeth Finchem
Bob Hazell
Jack Henslee
Jewell Hoffman
Bob and Ellen Hopkins
Max Hoyt
Bill Jayne
Bill and Dottie Kauffman
Jim Kelly
Leonard Librizzi
Henry and Anna Marks
Frank Morgan
Darlene Parker
Bob and Janet Radlow
Encarnacion Tamez
Tor Wold