

WebWhispers

Internet Laryngectomy Support

February, 1999

Welcome New Members!

Murray Allan

Richmond, BC, Canada
argus@home.com

Michael Boone

Louisville, KY
MikeBR12@aol.com

Johnny Boswell

Hagan, GA
jobo99@hotmail.com

Bonnie Caplinger

Benton, KY
bccap@hotmail.com

Larry Cook

Syracuse, NY
ltcufpo@msn.com

Ann D'Onofrio

Wickford, RI
AnnDonofrio@webtv.net

Robert Espeland

Vancouver, WA
budfrog@pacifier.com

Rorie Hastings

Milford, DE
rshastings@hotmail.com

Walter Hughes

Cincinnati, OH
Walt1929@aol.com

Continued on Page 2

Adhesives for the HumidiFilter

By: Terry G. Duga

There are two types of adhesives — Silicone Adhesive and Skin-Tac®. The Silicone adhesive seems to give a bit better adhesion. However, it is more expensive; more irritating to my skin; and it requires adhesive remover to get off of the skin. Skin-Tac® is easier on the skin and can be removed with rubbing alcohol. It also seems to last a long time. I am just now at the end of my first bottle of Skin-Tac® which I purchased over a year ago when it first went on the market.

An application of Shield Skin® or a similar product helps to protect the skin and get a better seal. The theory, as explained by the INHEALTH representatives at the IAL convention last summer in Indianapolis, is that the Shield Skin® acts to fill in the gaps, so to speak, in the skin. This gives a smoother surface to which the adhesive can adhere.

If you need a more secure seal, you can tape around the edges of the silicone base plate. 3M makes Micropore tape, a skin sensitive paper tape. Johnson and Johnson also makes a similar tape. Either buy 1/2 inch width or cut the 1 inch tape to 1/2 inch. Then put the tape 1/2 on the plate and 1/2 on your skin. If you really want a seal, paint the perimeter of the base plate with adhesive before applying the tape. I have found this to be overkill for my needs, but I have fairly low pressure voice. We are each different in our needs.

The base plates are soft. Over time, they get harder. When they get too hard, they don't stay sealed as well and they tend to cut into the skin. At that time, throw them away and get a new one. I have found that a base plate may last from two to three weeks to a month. I also tend to rotate two base plates so that different areas of my neck will be pressed as the plates harden.

I have tried the new base plate which has tape already attached. While I find them to be comfortable, they still have some bugs. In particular, the weld that holds the plate and tape together tends to be weak. It is prone to leak resulting in a whistling sound when you talk. INHEALTH is working on the problem.

The new base plates work without glue. The tape tends to hold better to the skin as the body heats the tape. Even in hot weather, the tape holds tight. If I have a day on a weekend when a reliable voice is not terribly important, I use one of the new base plates to give my neck a rest from the glue and silicone plates.

Vitamin E oil and Aloe help to soothe the skin after you remove the base plate and tape and glue.

In most cases, the HumidiFilter will reduce the production of phlegm. Reduction will come after five to seven days of consistent wearing, i.e., you must wear it each and every day.

Terry Duga, WebWhispers' Treasurer, is an attorney in Indianapolis. He can be reached at tduga@atg.state.in.us

Welcome New Members!

Robert King

Bakersfield, CA
beebo9803@aol.com

Nancy Kochan

Morann, PA
mkochan@penn.com

Roger Landry

Springvale, ME
feenix@cybertours.com

Stan Leibovitz

Santa Monica, CA
siggalert@webtv.net

Nelson Lim

The Phillipines
Nelson@dagupan.com

Betty Lindstrand

Maryville, TN
tobet@webtv.net

Teresa Moyer

Myerstown, PA
divinity@nbn.net

Liana Patterson

Louisville, CO
LianaHeart@aol.com

Richard Najarian

Bruce Medical Supply
Waltham, MA
BruceMedi@aol.com

Linda Peacock

Taylor, MI
ronp121@wwnet.com

Deborah Rhoades

Rochester, NY
debinroch@aol.com

Use of Altered Virus to Fight Cancer Looks Promising

By NICHOLAS WADE of The New York Times, December 22, 1998

A novel form of cancer treatment has neared the end of its preliminary trials with promising results at the same time as new research has cast doubt on its original rationale.

The doubts, not yet resolved, may mean that the treatment is less harmless to normal cells than thought. But it is also possible that the treatment may be applicable to a much wider range of cancers than previously believed.

The agent of treatment is a genetically altered adenovirus, one of the viruses that cause the common cold. Called Onyx-015 by its developer, Onyx Pharmaceuticals of Richmond, Calif., the virus is injected directly into tumors. Enormous doses can be used without apparent harm to the patient because the virus is designed to kill certain types of tumor cells but not healthy cells.

The treatment is based on recent insights into the basic genetics of tumor cells, and in particular the protective genes that are subverted when a cell becomes cancerous. The virus is designed for specific attacks on the many types of tumor cells that have knocked out a critical gene called p53.

Onyx-015 is being tested in patients with several types of cancer but the trials with head and neck cancers are furthest along. Onyx Pharmaceuticals reported last month that in 16 out of 26 patients with head and neck cancer, or 62 percent, the tumors had shrunk by more than half, and that in six of those patients the tumors had entirely disappeared.

In all cases, the patients received a standard chemotherapeutic drug as well as the virus, because earlier tests had shown the two agents in combination were more effective than either alone.

The results are impressive because the patients were at an advanced stage, all of them having failed to benefit from conventional treatments. But because the test is a Phase 2 trial, designed to explore the most effective dose with only a small number of patients, the results cannot be regarded as conclusive. The company now hopes, with Food and Drug Administration approval, to move to a Phase 3 trial, with enough patients to arrive at a statistically significant outcome.

Dr. James Arseneau, a doctor at the Albany Medical Center, is one of those testing the virus. Of the eight patients with head and neck cancer whom he has treated so far, "three have had really superb results," he said. "With one guy, the tumor all went away," he said. "In another, there's just an area of thickness but the initial mass has gone. The others had more minor responses. But given the situation, these people are in, with far advanced disease, I think it is really remarkable they have done as well as they have."

Meanwhile, on another track, several researchers experimenting with the Onyx-015 virus in the laboratory say they find it behaves rather differently than Onyx had proposed on the basis of its own laboratory tests. The question of exactly how the virus works bears both on its safety and on the range of tumor types it may be able to kill.

"Despite these bumps in the road, I still think it is a very exciting strategy," Dr. Lowe [another researcher] said. "If this virus doesn't work, probably some other virus will."

Copyright 1998 The New York Times Company

For an e-mail of the complete article with all of its technical details, contact Joe Casey at caseyjl@worldnet.att.net.

Continued on Page 4

Thank You!

To all of our contributing members.

Murray Allan	Charlie Anderson
Martha Anderson	Patsy Armstrong
Wayne Baker	Mary Bergquist
Ned Bienemann	Bob Blakeley
Grady Bradshaw	Ellen Byrne
Bev Buchanan	Walter Canney
Joe Casey	Scotty Chandler
Philip Clemmons	Carter Cooper
Terry Duga	Rudy Dupler
Clinton Dutchler	Norman Edelman
John Edwards	Bob Fitz
Paul Galioni	J.J. Gaston
Lorents Gran	Logan Grayson
Dave Geiwe	Bob Hazell
Dutch Helms	Jack Henslee
Bob Herzog	Betty Hildebrant
Bob Hoover	Bob Hopkins
Jerry Hough	Max Hoyt
Walter Hughes	Mary Jinright
Barbara Lakatos	Jean Lakatos
Charles Lamar	Ron Langseth
Len Librizzi	Scott Lowery
Clyde Lush	Bernard Mellecker
Ron Martin	Frank Morgan
Ken Morris	Richard Panger
Darlene Parker	Belva Pearce
Marianne Peereboom-Kooijman	
Pat Petrone	Janet Pounds
Bob Radlow	Mary Alice Renison
Red Rose Nu Voice Club	
Shirley Richardson	Pauline Rohm
Pat Wertz Sanders	Joseph Schad
Richard Scheele	Joe Schell
Clayton Schwalen	Herb Simon
Bobby Stanley	Harmon Swart
Diane Taliaferro	Chon Tamez
David Tillotson	Richard Tunnard
Al Weitzel	Tor Wold
Kay Yetter	

**Contributions to:
Terry G. Duga, Treasurer
6115 North Park
Indianapolis, IN 46620**

Internet Caveat? Not Really!

An article in the September issue of *JAL News* titled "Internet Caveat" expressed the opinion that medical advice available on the Internet is "...accompanied by a fair amount of hearsay and speculation."

Dick Scheele thinks otherwise.

Dick is a recent laryngectomee in Port Townsend, WA who is having difficulty developing real proficiency with esophageal speech. Dick asked for advice on the Internet on a TEP. His comments to our WebWhispers group are as follows:

"WOW! You guys are great. I asked for information to help me decide about a TEP and within a couple of hours I had a dozen answers.

You answered all my questions and offered advice I found very valuable. In two weeks, I have a meeting with my ENT and SLP to see if there is a reason I should not have a TEP. After that I will give it much thought and make my decision.

Thank you! Thank you! Dick Scheele"

Dick's response contains the real caveats about medical advice from any source, Internet or otherwise.

- Take all the inputs you can get.
- Consult your medical professionals for their expert opinion(s).
- Then, think long and hard about **your** final decision.

New England Medical Center Now Offers IMRT

Intensity Modulated Radiation Therapy (IMRT) is reported to be the most sophisticated form of computer-delivered radiation therapy currently available.

This innovative, 3-dimensional conformal radiation treatment delivers highly-focused radiation with minimal impact to surrounding tissues. Histori-

cally, the maximum dose that could be delivered to a tumor site has been restricted by the tolerance of nearby normal tissues.

The precision of the IMRT technology allows for more finite definition of the target zone, enabling a higher dose of radiation at the target zone with decreased probability of normal tissue toxicity.

New England Medical Center in Boston, MA is the only facility to provide IMRT in the Northeast region of the United States and was one of only six clinical sites in the world selected to develop this leading-edge technology. NEMC staff members have been instrumental in helping develop the customized software that is the foundation of this therapy.

The U.S. FDA recently approved this technology, which promises enhanced outcomes and substantial cost savings compared to related technology.

Additional information on IMRT is available at www.nomos.com. This Web site has a list of medical facilities in other areas which currently offer IMRT.

WebWhispers Nu-Voice Club



WebWhispers is the largest laryngectomee support group on the Internet and a member of the International Association of Laryngectomees.

The Club's officers for the 1998/1999 year are:

Dutch Helms	Webmaster
Joe Casey	President
Darlene Parker	Secretary
Terry Duga	Treasurer

WebWhispers welcomes all those diagnosed with cancer of the larynx or who have lost their voice for other reasons, their caregivers and friends and medical support personnel.

For information on membership, contact Dutch Helms at FantumTwo@aol.com.

All the Right Stuff!

by Glenn E. Peters, M.D.

As my life passes and my career continues to mature, I have become more reflective on what it means to treat and care for patients who have cancer.

Having never had cancer, I cannot sit here and profess to be able to tell you what you folks have endured — the fear and horror at getting the bad news; the dread of the unknown as you face therapy; the pain you suffer with your treatments; and the frustration you deal with as you adjust to your new lives as you go through your rehabilitation.

But I have watched and observed you very closely and it is on that basis that I can say the following: In every way cancer patients have what is known today as “all the right stuff.” You are a cross between a top level athlete, an explorer of unknown lands, an inventor, a psychiatrist, a soldier, and yes, even a mother or a father. Cancer seems to bring out the strengths in a person just when their life seems to falling apart (literally).

It will always be a source of constant amazement to me just how intensely patients rise to the occasion when faced with such devastating prospects. I have yet to meet a quitter - ever! You folks are the gutsiest, most determined bunch of folks I have ever met in my life. This is the human spirit, the desire to surmount seemingly insurmountable obstacles, the desire to LIVE in every sense of the word, which I see you folks bring into my clinic every day.

So to all of you I want to say a very special THANK YOU! You have taught me so much about life and, yes, sometimes death, but mostly life. Your spirit adds joy and meaning to my existence and challenges me every day to never let you down.

Dr. Peters of the Kirklin Clinic in Birmingham, AL is at Glenn.Peters@ccc.uab.edu.

Dr. Stone to Head 1999 Voice Institute

R. E. (Ed) Stone, Jr., Ph. D. has been selected as the Director of the 1999 Voice Institute which will be held in July in Reno, NV.

Dr. Stone is Director of the Voice Center of the Vanderbilt University Medical Center in Nashville, TN which was founded in 1991. The Center has advanced medical capabilities and special facilities, equipment and techniques for the diagnosis and treatment of a wide range of voice problems.

Jerry Hough, former IAL President, reports that Dr. Stone is an accomplished professional in his field, particularly on esophageal speech, and that he has been the driving force behind the Voice Institute of the Florida Laryngectomee Association for the past fifteen years. The Florida Voice Institute is the only sanctioned Voice Institute that trains SLP's to IAL standards. Further, it is the only outside group allowed to give the IAL test to SLP's.

WebWhispers attendees look forward to meeting Dr. Stone in Reno.

IAL Adds CAL

The California Association of Laryngectomees (CAL) has become the first North American regional laryngectomee association to join IAL.

CAL was founded in 1987 and currently has 30 member Clubs, 21 of which are also IAL members. The Association's three day conference is held annually, most recently last October in San Jose, CA. The Association will forego its 1999 conference in order to host the IAL's 48th Annual Meeting and Voice Institute in Reno, NV this coming July.

Elizabeth Finchem is CAL's current President.

Welcome New Members!

Ann Rogers

Franklin, MA
Babe@kersur.net

Joseph Schad

Boca Raton, FL
JosephSchad@webtv.net

Carl Schultz

Great Falls, MT
carlo@montana.com

Clay Schwalen

Concord, CA
clayinconcord1@juno.com

Jobeth Seder

INHEALTH Technologies
Carpinteria, CA
jseder@inhealth.com

Don Smith

Pensacola, FL
vbxpcola@aol.com

Pat Smith

Gresham, OR
ssilent@qcan.com

Lee Swett

Kinston, AL
gswett@alaweb.com

Larry Switzer

Ft. Lauderdale, FL
larryjo@powersite.net

James E. Vance

Jackson, TN
cutthroat@jaxn.com

Marianna Willoughby

Geraldine, AL
mwilloughby@farmerstel.com
