

GOLF IN CHICAGO BENEFITS TWO CHARITIES

Photo courtesy of Josh Wong Photography

CONTENTS

- 1 GOLF IN CHICAGO
BENEFITS TWO CHARITIES
- 2 THE LANE PROJECT
- 2 4TH ANGEL MENTORING
PROGRAM PARTNERSHIP
- 2-3 AN UPDATE FROM
CATHY LAZARUS, PhD
THNRC RESEARCH DIRECTOR
- 3 9TH ANNUAL THANC
FOUNDATION INVITATIONAL
GOLF TOURNAMENT
- 4 EVENT CALENDAR

The second Chicago THANC Foundation Golf Invitational took place on Monday September 19, 2011. Guests included many new donors, board members, physicians, and generous returning participants.

The biennial tournament began in 2008 with the generous support of the Dawson family, whose strong relationship with the THANC foundation and Dr. Urken commenced when their son, Duke, was diagnosed with a malignant neuroblastoma over 7 years ago. An intense search to find a physician able to treat Duke's unique and severe condition led them to New York and Dr. Urken. The close friendship and bond between Dr. Urken, the Foundation and the Dawson family has endured since that time.

"[Dr. Urken] did something that I never thought was possible by removing Duke's malignant tumor in a most difficult spot," remarked Duke's father Hanley Dawson IV. As a result, the family has been a long and generous supporter of the THANC foundation and its efforts to improve the lives of head and neck cancer patients.

The Glen Club in Glenview, Illinois—one of the top 100 Golf Courses ranked nationally—hosted the 2011 tournament. Although faced with a particularly challenging course and cloudy weather in the morning, tournament participants had a great time. Dr. Debra Pruzan noted that the generosity of the attendees was remarkable and heart-warming. As she recounted a bidding war that occurred over one of the live auction items, the gourmet pizza

party, Dr. Pruzan recalled that at the end of the playfully heated bidding war, the room discovered that two members of the Dawson family had vied for the same item. Participants engaged themselves with a day of golf, an evening cocktail hour and a buffet dinner.

The THANC foundation is enormously grateful to the entire Dawson family and their continued support over the years. Over 120 participants joined this year's golf tournament and dinner celebration, raising nearly \$155,000 for the THANC Foundation and Comer's Children's Hospital in Chicago, which supports the research of neuroblastoma expert, Dr. Sue Cohn.

The THANC foundation would also like to express gratitude to the event committee who made this event possible. The time and energy dedicated to hosting an event of this caliber is extraordinary and would not have occurred without their involvement. A special thank you to Carolyn Polos of The Patrick Dealer Group whose efforts and energy really made this event an incredible success.

Overall, this was another great golf outing whose significant contribution to our foundation will continue to help improve the lives of head and neck and thyroid cancer patients worldwide. ■



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PATIENT SUPPORT

THE LANE PROJECT

In March of 2010, the THANC Foundation received a very generous donation from board member, Eric S. Lane. After personally experiencing his dad's struggle with head and neck cancer, Mr. Lane recognized that the treatment process had not only affected his father, but his entire family. In addition to the difficulty of dealing with an unfamiliar disease, there was a disappointing absence of resources available to help and support this unique patient population. Motivated by this experience, Mr. Lane came to Dr. Urken with the vision of creating a readily accessible resource for patients and families experiencing the devastating effects of head and neck cancer. Specifically, Mr. Lane asked that the THANC foundation focus on the challenging and delicate task of explaining the often physically altering results of cancer treatments to young family members.

Inspired by this generous gift, the THANC Foundation has embarked on a mission to create an educational, web-based resource for family members of a patient undergoing treatment

for head and neck cancer. The website will offer accurate, age-appropriate information tailored to its targeted audiences. In particular, it will address common patient and family member concerns, including changes in appearance and ability to function, as well as overall side effects. The Lane Project will utilize experts in medicine, child psychology, strategy, and web-design to create a valuable resource that will fill a crucial gap in the long-term care of affected families. Ultimately, it will allow individuals to gain an improved understanding of the often devastating side effects of medically essential treatments.

The final execution of this endeavor will hopefully serve as a standard for future initiatives that deal with unique, but similarly difficult medical treatments. The THANC Foundation would like to thank Mr. Lane and his family for their generous support and vision, and express our enthusiasm in creating this novel and effective resource to assist head and neck cancer patients and their families. ■

RESEARCH

AN UPDATE FROM CATHY LAZARUS, PhD, THNRC RESEARCH DIRECTOR

FUNCTIONAL ASSESSMENTS

Since the creation of the Thyroid Head and Neck Research Center (THNRC) in November 2009, 465 functional assessments of voice, speech, tongue function, sensation, saliva production, swallowing, and quality of life have been conducted. During this period, 83 patients have undergone baseline and post-operative or post-chemoradiotherapy assessments to examine function over time.

INSTRUMENTAL SWALLOW EVALUATION

In March 2010 the Instrumental Swallowing Program was developed. Since that time 324 videofluoroscopic swallow studies (Modified Barium Swallow studies) have been performed utilizing the Kay Swallow Workstation. In addition to diagnosing the etiology of swallowing impairments. Many of these patients have been provided with therapeutic and dietary strategies that have allowed safe and efficient oral intake.

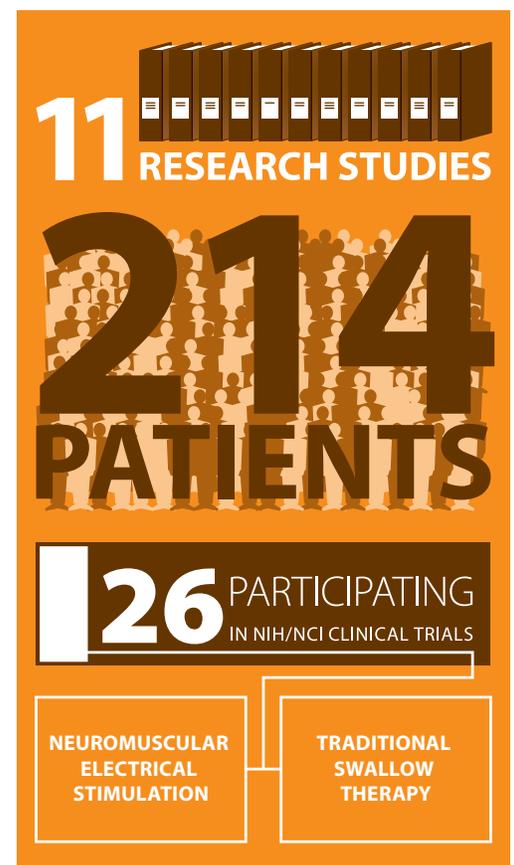
RESEARCH

Eleven studies have undergone Institutional Research Board (IRB) approval since the inception of the Research Center and are still underway. In total, 214 patients have participated in these studies. Of these patients, 26 have been involved

in the NIH/NCI clinical trial examining the effects of neuromuscular electrical stimulation paired with traditional swallow therapy on swallow functioning and quality of life in patients treated with surgery and/or chemoradiotherapy. Two new studies are currently pending IRB approval. One of these examines the effects of a new device designed to improve tongue strength in patients with weak tongue function for speech and swallowing. The other study examines pressure generation in the pharynx during swallowing utilizing manometry in patients who have undergone head and neck cancer treatment with surgery and/or chemoradiotherapy. The logistics of tissue banking for molecular/genetic testing of thyroid cancer is currently being discussed and will be finalized shortly. In addition, The Thyroid Cancer Care Collaborative (TCCC) website is in its final stage of completion.

MANUSCRIPTS & PRESENTATIONS

Two manuscripts have been accepted for publication in peer-reviewed journals within the past six months, with one other currently under review and another in press. Several other manuscripts are currently being developed and written, with data and statistical analyses being



11 RESEARCH STUDIES

214 PATIENTS

26 PARTICIPATING IN NIH/NCI CLINICAL TRIALS

NEUROMUSCULAR ELECTRICAL STIMULATION

TRADITIONAL SWALLOW THERAPY

BELOW Mr. Joe Carpentieri & Dr. Mark Urken. Photo taken at the 9th Annual THANC Foundation Invitational Golf Tournament. Image courtesy of Josh Wong Photography.

FUNDRAISING EVENT

9TH ANNUAL THANC FOUNDATION INVITATIONAL GOLF TOURNAMENT

The preparation that went into the 9th Annual THANC Foundation Invitational Golf Tournament, which took place on July 11th, produced an enjoyable event and raised significant funds to further the Foundation's mission. That balmy afternoon, 172 golfers played the immaculate course at the Glen Oaks Country Club. Since the fine weather extended into the early evening, dinner for our nearly 300 guests was served al fresco as the sun receded behind the country club.

As the evening banquet concluded, our speakers—Donald Levy and Dr. Mark Urken—took to the podium to voice their genuine gratitude to the audience. The event's guest speaker, Mr. Joe Carpentieri recounted his inspiring story of diagnosis and recovery, offering his heartfelt thanks to Dr. Urken and the Foundation.

TOURNAMENT RESULTS

As the evening pressed on, the results were determined for the awards. Philip Corbo won the Long Drive, Jeff Rich and Karren Kim got the Closest to Pin, and Leonard Bernstein, MD won the shoot-

out. Scott Mager, Brad Gruber, Jack Irushalmi, and Jeff Yohai won the Low Gross Foursome; Peter Jun, Tai Yo, Kevin Bae, and Insu Seo received Low Net Foursome; and Christine Ock, Mrs. Ys Choi, Karren Kim, and Unice Oh won the Low Net Women's Foursome.

FUNDRAISING RESULTS

The total bestowed to the Foundation this year from our devoted donors reached over \$625,000—exceeding the amount raised at last year's tournament by over \$10,000. Remarkably, while there were fewer golfers, the average individual donation increased significantly. The silent auction, which featured beautiful art from Will Barnet, a 300-mile excursion in a Bentley, an exquisite necklace of Honora pearls, and another 25 auction packages brought in an additional \$10,000.

Our sincere gratitude goes to the entire Levy Family, as well as the patrons and participants of the tournament, many of whom travel from all over the world year after year to support the THANC Foundation. To our volunteers—Bonnie

Spodek, Ree Hartwell, Barbara Johnson, Larry Levy, Joan Lehrer, Jessica Greenberg, Donna Levy, Dawn Levy, Janet Levy, Travis Wilson, and A. Omar Almodovar—who gave generously of their time and resources to organize, plan, and successfully stage the outing, thank you from the bottom of our hearts. We express our appreciation to Josh Wong and his team, the talented photographers who expertly documented the occasion. ■



performed by Hasan Husaini, the THANC Database Manager. In addition, three presentations are being submitted for the upcoming American Head and Neck Society meeting in April 2012 and the Dysphagia Research Society meeting in March 2012.

HEAD & NECK RESEARCH NETWORK (HNRN)

The HNRN is finalizing the database variables and has accepted two IRB-approved protocols submitted by the THANC Research Center. The database has been installed at the THANC site and data entry is scheduled to begin shortly.

NEW STAFF

The THANC Foundation Research Center has recently hired three new employees, and accepted one volunteer, to work on various projects within the THANC Research Center. These projects include chart review, entering data into various databases, and helping develop the patient education website. They are also assisting with IRB development and swallowing data analysis. Their addition is essential to the continued growth of our foundation, and as such we would like to welcome Will Karle, Sophie Scherl, Jason Clain, and Amy Plaut to the team. ■

SPOHNC

THANC is pleased to sponsor the Manhattan chapter of this national organization, which meets monthly on every fourth Thursday in the Institute's conference room at 10 Union Square East, Suite 5-B, New York, NY 10003.

4TH ANGEL MENTORING PROGRAM PARTNERSHIP

In an effort to supplement our patient support resources, the THANC Foundation recently partnered with The Scott Hamilton CARES initiative at the Cleveland Clinic and its 4th Angel Mentoring Program, which offers free, one-on-one, confidential outreach and support from someone who has walked the path of a head and neck or thyroid patient. The program began when Scott Hamilton identified 3 angels who helped him to survive testicular cancer—his oncology physician at The Cleveland Clinic; his oncology nurse; and his family and friends. What he felt was missing was a fourth angel, a peer who had a similar experience and would understand what he was feeling. He wanted to create a program in which cancer survivors or caregivers could discuss the experience with their peers. The resulting telephone-based mentoring programs established in 1999 currently have over 400 mentors who have experienced different cancer types and treatments.

HOW DOES IT WORK?

When a new patient or caregiver requests a mentor for support, the program staff at the Cleveland Clinic facilitates a match. The patient or caregiver mentor is paired with respect to diagnosis, gender, and age to ensure the mentor understands the patient and their experiences.

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