



Transplant Times

Newsletter of Transplant Awareness Organization of Greater Rochester

March / April 2010

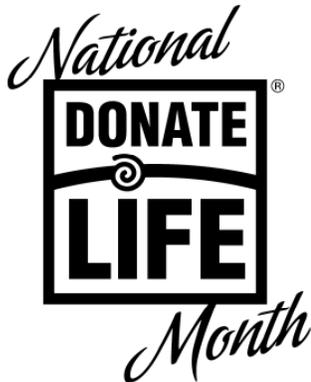
www.tao-rochester.org

1.888.664.1463

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April is:



TAO Meets

3rd Wednesday
of the Month
at the
Al Sigi Center
Cafeteria
1000 Elmwood Ave.
Corner of South Ave. & Elmwood Ave.
7:00 to 9:00 pm

ENTER DOOR 5
FOLLOW TAO SIGNS

Weight Loss Woes

Elizabeth Keirstead, RD, CNSD
Transplant Nutritionist, URM

As we welcome in the New Year, many are making those new years' resolutions. Resolutions to: lose weight, build a healthier lifestyle, exercise, meditate, go back to school, etc..... a list as varied as we are.

On the subject of weight loss, our tendency is to focus on a quick solution with minimal time commitment and fast results! As tempting as the next best quick diet may be, getting to the root of the problem and making healthy lifestyle changes that have long term impact on weigh control are key.

Hey!! Lose 15 pounds in a week!!!!

Americans have taken many approaches to enhance weight loss. There are many people who attempt weight loss using supplements and products found through advertisements or internet researches with promises to "lose 15 pounds in a week". In general people are led to believe that these products are "natural" and will do no harm; however, this is *not* the case.

According to a Nation Health Interview Survey, about 114 million people (more than 50% of the adult population in the U.S.) currently consume dietary supplements. The process in which these products are **regulated** and **evaluated** is **poorly understood by most**.

In the 2002 Harris Poll, the majority of consumers asked believed products were approved by government agencies and two thirds thought the government required label warnings identifying harmful effects. This is *not* the case. The majority of over the counter weight loss products have *NOT* undergone FDA (Food and Drug Administration) approval processes to assure safety and effect. It is *ONLY* if a product is found to have a dangerous effect that it will

be investigated by the FDA. It is estimated that 15% of US adults are purchasing this type of over the counter weight loss product.

In the October 15, 2009, New England Journal of Medicine, pages 1523-1525 entitled *American Roulette – Contaminated Dietary Supplements*, brings to light many new concerns to a new upcoming public health risk in the herbal and supplement industry.

Why should transplant patients be concerned?

Poor Processing: Pre transplant or compromised transplanted organs with decreased function may have the inability to process and eliminate by-products/metabolites from supplements.

Interaction: Over the counter dietary supplements may interact with current prescription drugs enhancing or decreasing the effects of their performance. For example, 'Alli Weight Loss Program' interferes with the drug Cellcept decreasing

Continued on page 2

Membership Meeting Guest Speakers / Topics

March 17, 2010

Chris Proschel, Ph.D.
"Stem Cell and Transplant"

April 21, 2010

Will be announced at the
March Meeting

("Weight Loss Woes" continued)

the body from absorption in the GI tract.

There are also reports of related liver damage from taking this over the counter product.

Secrecy: Inability for the medical staff to identify what specific ingredient(s) are causing harm. Because the manufacturer of these products is not regulated, they do not have to put everything on the label that may be in the product.

Un-proven: The promised effect and safety of a product are usually based on theory alone rather than actual scientific results; or, the results reported may have been obtained from the testing on animals, but not on humans.

Costly: Costly for the price you pay for them and costly for the problems you later have to pay for, such as a hospitalization or compromising your transplant.

How can this happen?

Prior to 1994, herbal products were considered food additives requiring their manufacturers to **show proof of safety**. Beginning in 1994 herbals/ supplements fell under a new bill called the Dietary Supplement Health and Education Act (DSHEA). DSHEA allowed for less regulation and less oversight concerning effect and safety of these products. This has resulted in reduced detection of supplements contaminated by toxic plant materials, heavy metals, and bacteria.

More serious contaminants that are purposefully used to hook people into addiction for that product or design the product to have faster desired effects includes: the addition of prescription medications, controlled substances, experimental compounds, or chemically altered agents. These ingredients have been found in products marketed for persons with

diabetes, high cholesterol or insomnia but mostly are found in sexual enhancement, optimal athletic performance and weight loss products.

Good examples of over the counter supplements that created serious health problems when used in over the counter products are a group of drugs known as; Fen Phen, Ma Huan, and Ephedra. The prescription based of these products, (Fenfluramine, Phenylpropanolamine, ephedrine) were FDA approved **prescription** weight loss products. Unfortunately, manufactures used these products in varying amounts to enhance the effects, misleading ingredient labels, and therefore the general public. Reports were found of products containing these drugs causing severe heart damage and lung disease (Pulmonary Hypertension). Although these were FDA approved medications, **WHEN USED AS PRESCRIBED UNDER PHYSICIAN SUPERVISION**, their use as additives in some over the counter products was unregulated. As a result, many people suffered serious health effects.

Buyers beware: Many of these products are purchased from internet sites, but are making their way to store front retail stores in the United States.

Take home message...

If your goal is to create a health lifestyle for yourself that includes losing weight...EXCELLENT, **GOOD FOR YOU!!!**

Be sure your time and efforts will provide you with a LIFETIME of health by enlisting a professional or supportive friend to help you:

- **Make a Food Plan:** make a plan for eating more healthy foods and **less** of the un-healthy ones;
- **Start Exercise:** if the concept is new to you, start small, *INVITE A FRIEND, and make it fun.*

Start slow and celebrate every day with the healthy lifestyle you are creating.

Contributions

We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.

*If we omitted you, please let us know so that we may post in next issue. **THANK YOU.***

David Cox, The Gap, Inc. – in memory of Chester Palozzi, Bonnie Haefner – in memory of Ray Lyman, Joanne Rourke – in memory of Dave Messmer, Norm & Phyllis Breen, Jerry Runion, Frank Imburgia, Ann Finger, David McNitt, Alma W Gilman, Peter R. Davis, Dennis L. Kovel and Patricia Legge

In Kind:

Kathleen McCaffery

LOCAL DONATE LIFE POSTER CONTEST FOR STUDENTS 5-12

The Finger Lakes Donor Recovery Network and Rochester Eye & Tissue Bank are co-sponsoring the 9th annual DONATE LIFE poster contest for students in grades 5-12.

If you know a teacher who would like to bring this to his or her students or you have a student in your home interested in entering this contest, please call Karen Guarino at (585) 272-7890 for more information.

You can download a criteria brochure and release form at www.retb.org, click on NEWS, then click on WHAT'S NEW. Deadline for this year's entries must be received on or before March 29, 2010.

Save The Date . . .

URMC Rochester River 5K Walk/Run

Sunday, April 11

Roundhouse Shelter
Genesee Valley Park
Rochester



What better way to mark Donate Life Month than by running and walking alongside your friends and family for the ninth annual Friends of Strong Rochester 5K River Run/Walk. More than 250 participants came out last year and raised \$5,200 for Strong Memorial Hospital's organ transplant program. Registration begins at 8 a.m. and the race starts at 10 a.m. Pre-registration fees for adults are \$20 per runner and \$15 for walkers. Children age six to twelve pay \$10 and receive a giveaway. Kids five and under are free. This year families can register for \$40 maximum fee.

In addition to treats and giveaways, there will be some new surprises for the entire family. For more information and to register visit <http://www.stronghealth.com/about/fos/walk.cfm>.

New York Alliance for Donation (NYAD)

Legislative Education Day

Tuesday, April 27, in Albany

Individuals needed to share personal transplant or donation experiences and to assist NYAD members in educating our Legislators on issues related to organ, eye and tissue donation. Travel accommodations, breakfast, lunch and dinner are provided.

Those who have participated in Legislative Education Day in the past have found it to be informative, rewarding and fun. For more information about this day-long effort, please contact Karen Guarino at (585) 272-7890 or by e-mail at kguarino@rehpb.org

Gift Wrapping and Results:

Over the course of two days in December, TAO members and their friends and families wrapped gifts at the Pittsford Barnes & Noble and raised \$75. This effort increases awareness for organ, eye and tissue donation as well as TAO and in the process raises some monies for TAO. Thank you to the following for their time and gift wrapping skills:

Debbie Yendrzeski and Amanda Loce
Shirley and Dave Newman
Rita Mascaro and Tony Mascaro
Karen Guarino and Aisha O'Mally
Joan and Jim Fyfe
Janice Odenbach and Linda Barnard
Kathleen McCaffery and Terry Nichols

VOLUNTEER OPPORTUNITIES FOR TAO MEMBERS

Have you ever thought of seeking out an opportunity to volunteer, perhaps working with people in the transplant/donation community?

At a Spring membership meeting, TAO will host various groups that need volunteers.

Rochester Eye & Tissue Bank, Finger Lakes Donor Recovery Network, and Harbor House will be a few of the speakers.

This presentation will give you an idea of what opportunities are out there to volunteer and how to become involved. So, if you've ever wanted to pitch in and didn't know how to go about it, this is your chance to get some information. Watch your next newsletter for the date.

TAO NOMINATION COMMITTEE WANTS TO HEAR FROM YOU

Are you interested in becoming more involved in TAO's future? If you have the desire, dedication and willingness to work with others, we want and need you. There are several positions on the Board of Directors that will need to be filled in 2010. TAO members or those outside the TAO membership are urged to consider becoming a Board Member or Officer. Help TAO continue to provide programs and support for those who need or have received transplants, their families and others.

If you are interested in learning more about the responsibilities of each, please contact Jerry Runion at 733-3422 or jgrunion@rochester.rr.com

Transplant Anniversaries

Cynthia Boyer-Green	Kidney	March	1996
Rita Callaghan	Liver	March	2001
Karen Gledhill	Kidney	March	1982
Robert Hadsell	Liver	March	1997
Thomas Louer	Liver	March	2004
Paula Mckay	Kidney	March	1995
Jan Sharp	Kidney	March	2005
Dennis Wittman	Liver	March	2007
James Graczyk	Liver	April	2002
Bob Ray	Heart	April	2004
Penny Sayles	Kidney	April	1998
Linda Marie Serenka	Kidney	April	2001
Asya Zarkhi	Kidney	April	2003
Ginger Zimmerman	Heart	April	1998

Run Like Hell — 5K

by Joanne Schum (bi-lateral lung recipient - September 12, 1997 due to cystic fibrosis)

The annual, unique 5K that Rochester is lucky to have was held October 24, just one week before Halloween.

The event allows accomplished runners to run for prizes, while others are running for fun, or walking, whatever your choice, and other like me, running for the cause Cystic Fibrosis (CF).

The Run Like Hell 5K began in 1998 at Johnny's Smoke Free Bar on Culver Road (this was the first and only smoke free bar in Rochester at the time.) A hearse led the group of runner's on their run. I believe there were just fewer than 100 runners that first year. Now the event attracts runners from all over the county. The number of runners is now nearly 500!!! The only cost to the runners is a \$20 fee, which is given to the Cystic Fibrosis Foundation in Rochester. You can raise additional money and donate as well, but no collecting money from supporters. Makes it nice, since we are mainly adults and not that cute to get sponsors. The race is still held at Johnny's, (new name "Johnny's Irish Pub"), since all bars are smoke free now.

The other great part of the race is the costumes. You are encouraged to wear a costume. There are prizes for best costume and also best "6-pack" costumes. "6-pack" is a group of 6 runners who must remain connected by rope, chain, hula-hoops, whatever you like, but you must remain connected through the entire race. This year the 2009 race had about 3 "6-packs of beer." They had much applause. There were "runaway brides", the "chain gang", McDonald French fries and other costumes. Great fun to watch.

I entered the race with my sister. I wore purple scrubs, with all sorts of medical equipment that CF patients are so used to; IV lines, oxygen tubing, syringes, and it made quite a swinging display. I also had a neon green sign on each side of my body that said "I have Cystic Fibrosis, I had a double lung transplant 12 years ago." It caught the eye of many and I talked to many people while waiting and promoted TAO to some folks who are pre and post transplant. My friend Kyra was dressed as a "nerdy sock hop girl". Cute! The race started with some dogs in the race too. Well, 5K is about 3.5 miles, something like that. I am good at running and walking, but running the whole thing is not my skill level. (I have a lung function of 65% at this point). So I walked some, and I also cut the route short. So I headed back to the finish line (same as the start line). This race is unique as they have the last ¼ mile going UP HILL!!!

My sister and I stood at the finish line and watched the people crossing. The comments from the crowd were priceless. One young man said, "Why does that group have nose plugs on? That has to be really hard." I turned to answer his question, "Well he wants the full CF experience, that is what it feels like to have CF, you can-

not breathe through you nose, and you breathe through your mouth, and your lungs are congested. Not easy and I am not talking running for a CF'er, but just walking." He said thanks, he had learned something. Someone had a stuffed elephant on their chest. Someone in the crowd said, "what is that costume?" Again I could answer, I had the knowledge, "that person is showing what it feels like to have CF, like an elephant sitting on your chest all the time". Again they thanked me for the insight of the elephant.

I finally crossed the finish line after it looked like most people had finished. I believe I came in about 406 out of 433!! Not bad at all I think.

So if you want to have a great time, and be entertained, this is the event to check out. If you are not a runner, just watch. At the end of the road that we started at, there was Sandy McNitt, cheering me on. Her brother was in the race too. I think he came in the top 20.

I have thought of additional items for my costume... IV Pole with wheels. Might need to improve the wheels so they can take the entire race.

Here is a picture of Kyra and me before the race began. Oh yeah, the costumes I chose from were from Goodwill. I picked the purple scrubs, as purple is the color for CF!

Joanne Schum (R) pictured with her friend Kyra



United Network for Organ Sharing

Candidates listed as of 2/5/2010

83,321	Kidney
15,806	Liver
3,101	Heart
2,212	Kidney/Pancreas
1,865	Lung
1,492	Pancreas
233	Intestine
72	Heart/Lung

105610

TOTAL

Total may be less than sums due to patients in multiple categories

www.unos.org

Thank You

"Thanks for being there! We enjoyed Santa and his elves and your encouragement throughout our stay. We request membership to your group and hope to become actively involved more in the Central NY area."

Dan and Suzi Phillips

Norm, Phyllis & Clairissa Breen and Norm's brother Bill for making blankets for our blanket project

Wishes of Wellness To...

Our healing thoughts go out to Sandy McNitt, lung transplant January 27 at the Cleveland Clinic



Our Condolences ...

Our deepest sympathies go out to Norm Breen on the passing of his mother and to Rita Mascaro and family on the passing of Louis Mascaro (30 year kidney recipient, live donor)

If you are aware of members that we should list in *Wishes of Wellness*, or to express our condolences to, please call TAO and leave a message at 1-888-664-1463.

Holiday Recognition Dinner

On a balmy winter night, 50 TAO members enjoyed the Holiday Recognition Dinner held at the Green Lantern Inn, Fairport, NY. Jerry Runion, TAO President, acknowledged recipients, caregivers, and three living kidney donors that were present, as well as those who helped TAO throughout the year.



The evening was spent sharing stories of transplantation, having an opportunity to talk with members and enjoying good food. "It's a good chance to enjoy a night out with members outside of a meeting," said Bonnie Haefner. "It was nice to see some members that can't



generally make the meetings," said Karen Guarino, who attended with her husband, Brian.

If you couldn't make it out for the party we hope you'll join us at a meeting or at the annual picnic in June.

Caregiver Responsibilities - by Mary L. Morey

Celebrate the gift that keeps on giving – The Gift of Life

As Mary Morey awaited her husband Larry's heart transplant, she took the time to understand her responsibilities as a caregiver. The following outlines what those responsibilities would be.

Educate – Learn everything in relation to the transplant program. Teach yourself all avenues of patient care physically, emotionally and mentally for a new life of good health.

Illustrate – Show concern, ask questions on changes that you and the patient will experience together. Understand that we do not live together in our daily routine. He's in the hospital and I'm at home part of the week.

Motivate – Decide together your new lifestyle, home environment precautions and medicine routine together. Discuss dietary and exercise on a daily basis to ensure continued health improvement. For each other, push forward – move on together with each other.

Orchestrate – Love and support each other no matter what the future holds for you together with God's love each day.

Transplant Times

Submission Deadline

**For May / June issue:
Monday, April 5, 2010**

**Articles /ideas email to:
auggieday@aol.com or
kbliek333@gmail.com
or send by mail to:
TAO, PO Box 23552, Rochester,
NY 14692-3552**



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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- checkbox New Member checkbox Renewal checkbox \$10 Family checkbox \$10 Institutional
checkbox unable to make dues payment at this time Date _____

Extra contributions to help our organization are always welcome, and are tax-deductible. Make checks payable to: TAO of Greater Rochester, PO Box 23552, Rochester, NY, 14692-3552.

Name (please print) _____ Spouse/companion _____

Address _____ City _____ State _____ Zip _____

Phone () _____ E-mail _____

- checkbox Candidate checkbox Recipient checkbox Family Member checkbox Donor Family checkbox Friend checkbox Professional

Candidate/Recipient information: # of Transplants _____ Hospital _____

Date(s) _____ Organ(s)/Tissue(s) _____