



AGENDA

Turner Syndrome Foundation Quarterly Meeting

WHEN: **Saturday, October 23, 2010, 11:30 a.m. – 3:00 p.m.**
WHERE: Secaucus Public Library
1379 Paterson Plank Road, Secaucus, NJ 07094
COST: FREE... Donations accepted

WELCOME!

11:30 a.m. REGISTRATION and LUNCH

12:00 p.m. EDUCATION

Topic: 'Advocacy Across the Lifespan Booklet release and lecture with TSF Legal Advisor, Valerie A. Powers Smith, Esquire'

With thirteen years of experience in the field of special needs and disability law, **Valerie A. Powers Smith, Esq.** brings to **Slovak Baron & Empey, LLP** the following highly specialized practice areas: health care insurance, disability insurance, Medicaid, Medicare, special needs trusts, trust administration, estate planning & administration, guardianships, and accessing federal and state government disability-based benefits.

Over this time, Valerie has concentrated her legal work in the area of health care law and has vigorously advocated for families and people with disabilities to gain medically necessary care from private insurance companies, Medicaid, Medicare, and other health insurance providers. She has additionally focused her practice in the areas of special needs trusts and estate planning and routinely advise families, executors, and trustees on the area of special needs law and the administration of the same.

Valerie has written extensively on a variety of disability law topics, has co-authored several publications on accessing adult services, Medicaid, and health insurance; and is a regular contributor to the Arc of New Jersey's Healthy Times Newsletter. She has also lectured for disability-related groups throughout Pennsylvania, New Jersey, and D.C. Valerie currently sits as one of the 12 members appointed by the Governor to the New Jersey Medical Assistance Advisory Council and is serving her second three-year term. She is also a member of the Board of Directors for Easter Seals of Southeastern Pennsylvania and Caregivers of New Jersey; and an Advisory Board member of Family Voices New Jersey & Autism Family Services of New Jersey. On the national level, Valerie also serves as a legal consultant for MITO ACTION; and is on the legal advisory board for the Turner Syndrome Foundation, Inc.

Valerie can be contacted via email at powers@sbelawyers.com.

1:00 p.m. EDUCATION

Topic: 'Understanding Celiac Disease with Margaret Weiss Masiello, RD'

Three million Americans have celiac disease and only 3% know it! Come hear a discussion about this often misdiagnosed disease, including symptoms and paths to diagnosis for those at risk. Other topics to be covered: the gluten free diet, current allergen labeling regulations and dining out strategies. A question and answer session will follow the presentation.

Margaret Weiss Masiello, RD, graduated with a BA in Psychology from William Smith College, studied Nutrition at the College of Saint Elizabeth, and completed her Dietetic Internship at the University of Medicine and Dentistry of New Jersey. She also holds a Certificate in Adult Weight Management from the Commission on Dietetic Registration. She has worked as a clinical dietitian for Robert Wood Johnson University Hospital, the ALS Foundation of Greater New York and as a consultant to several supermarket chains regarding celiac disease and the gluten free diet. In addition to her practice as The Mobile Dietitian, Margaret is currently the Clinical Coordinator for the Kogan Celiac Center of the Saint Barnabas Health Care System.

Margaret Weiss Masiello, RD, Clinical Coordinator, Kogan Celiac Center
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2:00 p.m. **INFORMATION**

Committee Reports: Education, Publicity, Fundraising, and Events

- Volunteers are needed for committees, exhibit events
- TS Video Diaries – email hpolise@tsfusa.org to register
- Holiday Event – Sarah Petrassi – email spetrassi@tsfusa.org
- Marathon registration – Donna Villavicencio – email dvillavicencio@tsfusa.org

Upcoming events:

- 10/27 AAP Annual School Health Nurse Conference exhibit The Palace, Somerset, NJ
- 11/4-5 NJEA Annual Teacher's Convention, Atlantic City, NJ
- 11/9-10 AAP Conference exhibit, Atlantic City, NJ
- 11/18-19 Dallas Convention Center World Congress, TX
- 12/19 Annual Meeting Holiday Event, Landmark II, Rutherford, NJ

NEW!! All are invited to create a personal page on the TSF website! Upload a photo and share personal stories to encourage support.

Click on the link on the home page www.TurnersyndromeFoundation.org for technical assistance, Contact jtaglieri@tsfusa.org

2:30 p.m. **SUPPORT**

In remembrance of Dr. Chayim Newmark:

Dr. Chayim Newmark, Medical Advisory Board of the Turner Syndrome Foundation, passed away on July 14, 2010. He leaves behind a wife and seven children. Memorial donations may be mailed to: Yeshiva Ktana Newmark Fund, Yeshiva Ktana, 1 Main Avenue, Passaic, NJ 07055
A TSF Scholarship Fund will be established in his name. Dr. Newmark was a true champion for TS, and he will be missed.

SAVE THE DATE ~ Quarterly Meetings 2011

Saturday, January 22
Saturday, April 30
Saturday, July 23
Saturday, October 22

TurnerSyndromeFoundation.org
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