

December 7, 2010

Mr. John S. Pistole, Administrator
Office of the Administrator - TSA-1
Transportation Security Administration
601 South 12th Street
Arlington, VA 20598

Dear Mr. Pistole,

Members of the bladder cancer community and people living with ostomies throughout the U.S. want to thank you for reacting swiftly to the complaint of bladder cancer survivor and ostomate Thomas Sawyer. We appreciate that you contacted him personally to apologize and that you are willing to find ways to improve the TSA's screening process for people with ostomies and other medical issues.

Bladder cancer is the fifth most commonly diagnosed cancer in the US. As a result of bladder cancer and other medical issues such as colorectal cancer and Crohn's disease, hundreds of thousands of people in the US live normal daily lives with ostomies. Although the TSA includes information about ostomies in the training of your Transportation Security Officers (TSOs), we believe that more information and training about how to be sensitive to travelers' medical conditions is needed. This is especially true because ostomies and other medical conditions and devices that previously had not shown up in security screenings will show up more frequently in full body scans.

In addition to ostomies, the constituencies of the undersigned organizations often live with indwelling ports, catheters, PICC lines, feeding tubes, and insulin pumps – all of which may show up as anomalies on full body scans and should not have to be removed for a security screening. In fact, in some cases, removal of these devices can quickly precipitate medical emergencies.

We encourage TSA to develop educational materials, using pictures or demonstration devices, to explain to your officers various different medical issues and the specific TSA procedure for screening travelers with these issues. As part of this effort, we urge TSA to develop clear, uniformly-applied policies that reasonably limit the use and scope of "pat downs" for these travelers. For instance, such a policy might limit the pat down to the location of a medical device only or dispense with it entirely under specified

circumstances. This would help prevent situations, such as that experienced by Mr. Sawyer, where the TSOs were clearly unaware of the sensitivity surrounding an urostomy pouch.

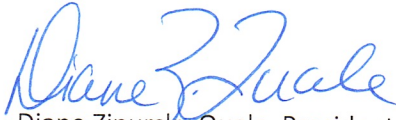
Additionally, TSOs must have more training to ensure that the officers listen with respect to travelers who explain they have medical issues and be prepared to work with them to preserve their dignity. Travelers with medical conditions and disabilities deserve to be treated with respect, regardless of what appliance, catheter, port, or other medical device is attached to their bodies.

Please also consider including someone who lives with one of these devices as part of your training sessions. What better way to provide a complete overview of the issues and need for sensitivity? The organizations listed below would be happy to connect your trainers with people who live with these medical issues every day.

It is our understanding that the TSA has developed an information card for people with medical issues to help communicate with TSOs. However, we have been unable to find this information card on the TSA website. We urge TSA to make this card publicly available as soon as possible. Each of the undersigned organizations would be happy to help publicize this communication card to our members.

Clearly, a one-size-fits-all approach for screening has not worked for people living with ostomies and those who use medical appliances and devices. Each of the undersigned organizations looks forward to working with you in the future to improve the ability of Americans with disabilities to be adequately screened with the respect and dignity they deserve.

Sincerely,



Diane Zipursky Quale, President and Co-Founder
Bladder Cancer Advocacy Network

Jennifer C. Jaff, Executive Director
Advocacy for Patients with Chronic Illness, Inc.
www.advocacyforpatients.org
860-674-1370

Lyle Dennis
American Association for the Study of Liver Diseases
www.aasld.org
703-299-9766

Gary Gross, Director of Legal Advocacy
American Diabetes Association
www.diabetes.org
703-299-2023

Kathleen Teixeira, Director of Government Affairs
American Gastroenterological Association
www.gastro.org
301-654-2055

Lori Ennis, Executive Director
The American Neurogastroenterology and Motility Society
www.motilitysociety.org
734-699-1130

Dr. Peggi Guenter, Director
Clinical Practice, Advocacy and Research Affairs
American Society for Parenteral and Enteral Nutrition
www.nutritioncare.org
610-649-7994

Linda Reinstein, CEO and Co-Founder
Asbestos Disease Awareness Organization
www.AsbestosDiseaseAwareness.org
202-391-1546

Mary-Angela DeGrazia-DiTucci
President/Patient/Founder
Association of Gastrointestinal Motility Disorders, Inc.
www.agmd-gimotility.org
781-275-1300

Carlea Bauman, President
C3: Colorectal Cancer Coalition
www.FightColorectalCancer.org
703-548-1225 ext. 11

Mary Schluckebier, Executive Director
Celiac Sprue Association
www.csaceliacs.org
877-272-4272 Ext .1006

Andrew Spiegel, Chief Executive Officer
Colon Cancer Alliance
www.ccalliance.org
202-434-8996

Amy Friedman, Director of Advocacy
Crohn's and Colitis Foundation of America
www.ccfa.org
800-932-2423

Linda Aukett, Chairperson
Digestive Disease National Coalition
www.ddnc.org
202-544-7497

Thelma Thiel, CEO
Hepatitis Foundation International
www.hepfi.org
800-891-0707

Dane Christiansen, Development Coordinator
International Foundation for Functional Gastrointestinal Disorders
www.iffgd.org
888-964-2001

Barbara Gordon, President and CEO
Interstitial Cystitis Association
www.ichelp.org
301-775-4054

Michael Smith, Vice President
Gastroparesis Patient Association for Cures and Treatments
www.g-pact.org
917-969-7092

Alice Bast, Founder & President
The National Foundation for Celiac Awareness
www.celiaccentral.org
215-325-1306

Jane Holt, Co-Founder
National Pancreas Foundation
www.pancreasfoundation.org
866-726-2737

Joan Bishop, Executive Director
The Oley Foundation
www.oley.org
800-776-OLEY

Bonnie McElroy, Executive Director
Pull-thru Network, Inc.
www.PullthruNetwork.org
205-978-2930

David Rudzin, President
United Ostomy Associations of America, Inc.
www.uoaa.org
800-826-0826

Paul J. Hastings, President and CEO
Youth Rally Inc.
www.rally4youth.org

cc: Secretary Janet Napolitano, Department of Homeland Security
Department of Homeland Security, Office for Civil Rights and Civil Liberties, Review and Compliance
Rhonda Basha, Director, Office of Disability Policy and Outreach, TSA
Kimberly Walton, Special Counselor, TSA
Kareem Dale, Special Assistant to the President for Disability Policy