

# CDTRP MEDIA WORKSHOP ON ODT & HEALTH LITERACY

April 20, 2022



## POST-EVENT REPORT

## BACKGROUND

Do you find that media coverage sometimes gets it wrong about organ donation and transplantation (ODT) and the medical reality? Do you find that health experts are not sufficiently involved or engaged in the public, media, and social discourse? The mission of the Canadian Donation and Transplantation Research Program's (CDTRP) Media Workshop on ODT and Health Literacy is to bring the media and ODT experts together to provide tools and information necessary to convey a clear and accurate message. We are convinced that by working together, the right information will reach the right ears.

## OBJECTIVES

This Workshop aimed to:

1. Bring together journalists and media specialists (traditional and social) with researchers, health professionals, and patient, family and donor partners with expertise in the field of donation and transplantation and;
2. Engage conversations for the goal of making it easier for accurate information and meaningful stories of public interest to reach Canadians.

## OVERVIEW

The CDTRP was proud to launch its **Media Workshop Series on Organ Donation and Transplantation (ODT) & Health Literacy** on **April 20, 2022**. Through this initial Workshop entitled "**Learning from each other**", we engaged the media and various players working in ODT in discussions that will hopefully lead to greater collaboration – contributing to the building of a strong culture of organ and tissue donation.

## PLANNING COMMITTEE

The Planning Committee included:

- **Dr. Marat Slessarev** - Adult Intensivist at London Health Science Centre (LHSC)
- **Dr. Sonny Dhanani** - Chief of the Pediatric Intensive Care Unit at Children's Hospital of Eastern Ontario (CHEO)
- **Dr. Aviva Goldberg** - Pediatric Transplant Nephrologist at Health Sciences Centre Winnipeg
- **Ms. Mary Beaucage** - Patient Partner
- **Ms. Linda Powell** - Caregiver Partner
- **Ms. Sandra Holdsworth** - Patient Partner
- **Ms. Shilpa Raju** - Patient Partner
- **Ms. Sherrie Logan** - Caregiver Partner
- **Dr. Patricia Gongal** - CDTRP Executive Director
- **Ms. Stéphanie Larivière** - CDTRP Communications Manager

## WORKSHOP AGENDA

1. Welcome remarks - Dr. Lori West
2. Intro presentation - Ms. Belén Velasco Conquero
3. Media presentation - Prof. Timothy Caulfield
4. ODT presentation - Dr. Aviva Goldberg
5. Panel discussion
  - a. Dr. Shaifali Sandal
  - b. Ms. Heather Badenoch
  - c. Dr. Blair Bigham
  - d. Dr. Stephen Beed
6. Open discussion

Detailed information on the presenters, moderators and panelists can be found on the [CDTRP website here](#).

## HOW CAN THE MEDIA AND THE ODT COMMUNITY WORK WITH EACH OTHER?

In the opening presentation, we learned about the "Spanish Model" with **Belén Velasco Conquero**, Communications with the National Transplant Organization (ONT). This organization is the Spanish national authority responsible for the oversight, coordination and organization of the donation and clinical use of organs, tissues, and cells. Communication has always been part of the well-known "Spanish Model" in organ donation and transplantation as one of its enormous strengths. This good relationship with journalists (national and international), as well as the alliances that ONT has created with other stakeholders has helped them to spread the message effectively and accurately.

We then learned about why media matters with **Prof. Timothy Caulfield**, who offered the media perspective of the Workshop. He highlighted the impact and influence that the media can have on policy, expectations and clinical decisions. He also pointed out that the media put forward a lot of stories, but little science per se. He then guided us through the concept of "rule of rescue" in the context of public solicitation, emerging technologies and policy making.

Following this presentation, we heard about the organ donation and transplantation (ODT) perspective with **Dr. Aviva Goldberg**. Dr. Goldberg talked about respect with the stories of individuals in their transplant journey as well as avoiding science hype and guided us through the "miracle" language. She also emphasized that transplantation is not a cure in order to put certain stories into perspective.

To open discussions, we invited four panelists to comment on the presentations and bring their perspectives to the discourse. We first heard from **Dr. Shaifali Sandal**, followed by **Ms. Heather Badnoch**, **Dr. Blair Bigham**, and finally **Dr. Stephen Beed**. The discussion was moderated by **Cristina Howorun**, journalist and documentary producer and **Mary Beaucage**, patient partner and transplant recipient.

## ATTENDEES

In total, **94 participants** registered for the Workshop from **36 different cities from Canada and around the world**. International participants came from the United Kingdom, Spain, Australia, and the United States. Participants included donation and transplant researchers, clinicians, communications specialists, journalists, and patient, family, and donor partners.

The participants remained very engaged throughout the presentations, panel discussions, questions & answers, and contributed to active discussions with speakers and with other participants.

Below is an overview of some of the comments and questions raised during the Workshop's discussions. This shows how much more work needs to be done to engage strong and effective collaboration between the media and the ODTC.

"How do we create the feeling that regular people can get in the inner circles? I know it's not as difficult as people think to get in touch with someone from the media, but I think a lot of people are intimidated to reach out to a media person to share their story."

"In the context of his pandemic reporting, writer Ed Yong has spoken about the typical media focus on individual stories, and how this may lead to missing the forest for the trees, i.e., the media missing or minimizing the big picture issues. Could this same dynamic be at play in donation/transplantation reporting, with the emphasis on individual 'miracle' stories?"

"It's a two-way street - always feel free to ask [a journalist] more about what the story is about and how you can help contribute to that story."

"A public appeal can bring in interested parties that even if they might not qualify to donate to person making the appeal, they may stay in the system and go on to donate to someone else."

"There is also a difference between selecting an org (organization?) rep for an interview and a patient. An org (organization?) rep in on message while a patient tells their own story. Both can receive support or prepare."

"Story NOT being told: Hospitals don't want to be responsible for social media going wrong, so I know that many programs fear encouraging recipients to use social media to share their story (the big tell)."

"Another important element is that the transplant procedure is just the surgical piece, which is brief - most of transplant medicine is long term care and health after transplant."

"The issue of access and privacy for filming / telling stories in hospitals can be further explored with bioethicists/legal experts in Theme 1. How can we improve access for journalists to tell compelling stories in hospitals?"

"I believe we don't talk about the missed donation opportunities in Canada - everyone is always shocked when you point out that while over 300,000 Canadians die per year, yet we only have 700 deceased donors in total per year. There is a huge disconnect between how often the public thinks organ donation occurs and what is reality."

"Question for Media: How do you get people to talk that work within these systems e.g. front line staff? People are worried about losing their jobs and worry about speaking up about HOW BAD it really is. Patients are worried about their transplant coordinator negatively impacting their care e.g. not prioritizing their work up if they say something."

## POST-EVENT

The Workshop has been recorded and posted on the CDTRP's YouTube channel. A publication on the CDTRP's website summarizing the Workshop and thanking participants has also been done and shared on social media platforms ([Twitter](#) and [Facebook](#)).

[VIEW RECORDING](#)

The next Workshop is scheduled for **Tuesday, May 17, 2022, from 2 to 3:30 pm EDT**. This will be a joint event with the team of the Health and Law Institute from the University of Alberta: Alessandro Marcon, Timothy Caulfield, and Robyn Hyde-Lay. This second Workshop, "**Engaging the public online during policy change**" will focus on social media and individuals will share their recent and extensive experience engaging the public online. They will discuss the complexities around hosting and moderating discussions, creating accurate informative content, and responding to misinformation. They will highlight challenges and lessons learned. Sharing their experiences will contribute to the ongoing discussions around how to best engage the public online for individuals, employers, and institutions.

Participants who would like to be kept up to date for future media events are encouraged to subscribe to the [CDTRP's weekly newsletter here](#).

For any questions concerning past or future CDTRP events, you can email Stéphanie Larivière, Communications Manager at [slariviere@cdtrp.ca](mailto:slariviere@cdtrp.ca).