Transplant Unwrapped Ambassador Guide

Thanks for Signing-Up as an Ambassador. Please review this guide to become familiar with the program and the next steps.

Basic Steps to Ambassador Activation:

- 1. Review this handbook.
- 2. Watch the <u>Ambassador Training Video</u>. You can <u>download the presentation</u> slides.
- 3. Be on the lookout for an email from Kayla (kayla@transplantunwrapped.org) for you to approve your bio and profile picture on the "Meet the Ambassadors" page of the Transplant Unwrapped website.
- 4. Approve your information on the website by replying to Kayla's email. Once this is confirmed, you will become an active Ambassador, and participants can start contacting you.

What is the Transplant Unwrapped Ambassador Program?

The purpose of the Transplant Unwrapped Ambassador Program is to provide peer-to-peer information and emotional support (not medical advice). The goal is to offer a network to those going through the complex medical journey of intestinal disorders, encouraging patients and caregivers to stay active and engaged in their care and feel well-supported across the short bowel, intestinal failure, intestinal rehabilitation, and intestinal and multivisceral transplantation community.

As experienced intestinal patients and caregivers, Transplant Unwrapped Ambassadors give patients and caregivers an opportunity to express feelings, talk about concerns, and ask questions of someone who has been there, such as coping with diagnosis, treatment, and medication side effects. Most importantly, Transplant Unwrapped Ambassadors offer understanding, support, and hope because they themselves, or their loved ones, have navigated the complex intestinal world. Please note, Transplant Unwrapped Ambassadors do not provide medical advice.



Transplant Unwrapped Ambassador Guide

A Transplant Unwrapped Ambassador:

- Understands the Transplant Unwrapped mission and recognizes the value of the resources and connections, and how they impact the members we serve.
- Helps Transplant Unwrapped outreach and support efforts through the use of their time, personal skills, and interests.
- Understands that the Transplant Unwrapped mission depends upon the full
 participation of all members of the intestinal failure, intestinal rehabilitation, and
 intestinal transplantation community and remains impartial (i.e., not a spokesperson
 for or referring patients to particular medical centers, homecare companies etc.).
- Provides information, guidance, and emotional support to those involved in the rehab or transplant process.

Who can become a Transplant Unwrapped Ambassador?

- An "experienced" (had a long time, had many treatments for) patient, or caregiver living with Short Bowel Syndrome (SBS), intestinal failure, or other intestinal dysfunction, such as Chronic Intestinal Pseudo Obstruction (CIPO)
- Patient, or their caregiver, who has gone through intestinal rehabilitation.
- Patient, or their caregiver, who has gone through intestinal or multivisceral transplantation.

Basic Requirements and Expectations:

- 1.>18 years of age (13-18 Parental Consent).
- 2. Willing to speak with others about your experiences, including via email, online chat, Facebook messenger, and 15-30 minute one-on-one support calls.
- 3. Represent your transplant center and Transplant Unwrapped with *dignity and respect* at all times. Refrain from negative comments about doctors, centers, etc. The goal is to provide helpful information to educate and support our peers, not to gossip.
- 4. Agree to Transplant Unwrapped's Terms of Use and Disclaimers and the <u>Support</u> <u>Programs Code of Conduct.</u>
- 5. Refer to medical professionals if asked for medical advice about a particular medical situation or condition. We are not here to diagnose, treat, or cure any illness, our support programs, website, and other resources are solely for support and informational purposes only, and **should not be substituted** for a professional's medical advice or opinion.

Participant Appointment Requests

01

A participant sends you an email. Please check your "junk" mail frequently.

Intermediate Step **TU Ambassador leader** sends the participant a welcome email once they fill out the participant form. **You go to Step 2.**

0 2

Reply to the request in **5 business days.** Refer to the email template below for what to include.

03

Confirm call with the participant. Try to have the actual call *within 7-14 business days* after initial communication was made.

04

Have your call. You can decide if you want continued communication after the intro call.

05

Send a follow-up email to ambassador@transplantunwrapped.org. See below for template and what to include.

Please Note:

On ALL email correspondences between you and participants...



cc'

ambassador@transplantunwrapped.org

Email Template: Setting up First Meeting (Step 2)

Email One: Setting Up the First Meeting

What to include in this email:

- Your name
- Best way to contact you
- 3 possible dates/times for call

Email Sample:

Replying to: Participant

Subject: TU Ambassador (Your Name) Intro Meeting

CC: <u>ambassador@transplantunwrapped.org</u>

Hi (participant name),

Thank you for reaching out. My name is [Kayla] and I am a Transplant Unwrapped Ambassador. The best way to contact me is through [email or phone number].

I have found 3 dates/times that would work for me for a call, do any of these work for you?

1.January 4, 2021 at 7:00 pm EST

2.January 6, 2021 at 4:00 pm EST

3.January 8, 2021 at 3:00 pm EST

I am looking forward to speaking with you. In the meantime, if you have any urgent questions, you can visit the <u>"Ask the Expert"</u> section of the Transplant Unwrapped website!

Stay well, Kayla

Email Template: Meeting Follow-Up (Step 5)

Email Two: Meeting Follow-Up

What to include in this email:

- You and Your Participants name.
- Date of chat or call.
- One or two short sentences on how the call went.

Email Sample:

Send to: ambassador@transplantunwrapped.org

Subject: TU Ambassador (Your Name) Intro Meeting Follow-Up

Hi,

I just completed my meeting with (participant's name). It took place on (January 8, 2021 at 3:00 pm EST). The meeting went well. We discussed the (participants) difficulties of being on the transplant waitlist.

Thanks!
[Your Name]

Transplant Unwrapped Ambassador Do's and Dont's

"Do's"

- Listen actively to your participant.
- Be respectful and reliable.
- Emphasize the positive.
- Try to find common interests other than medical things, like you both like to bake or watching a certain television show.
- Be open to learning new things from your menteeremember it is a two-way street.
- At the end of your meeting, summarize what was discussed and make sure you have made plans for your next communication.

"Dont's"

- Do not offer medical advicewe will not be held liable for any advice given. See our disclaimer policies and terms of use.
- Do not try and fix your participant's problems.
- Do not be judgmental or overly critical of your participant's decisions with their care.
- Do not take over the conversation and do all of the talking.

Transplant Unwrapped Ambassador Helpful Hints

General Introduction: Get to know one another. Share your intestinal condition, the type of intestinal rehab or transplant you each received, how you are currently doing, hobbies, and anything else you find would be useful intro information.

Ideas of Questions for Introductory Call/Chat:

- Where do you currently live? Where are you originally from?
- What type of intestinal rehabilitation or transplantation are you pursuing, if any?
- What rehabilitation and transplant center do you go to, if any?
- How long have you been going to that particular center?
- What are you most concerned about when it comes to intestinal rehab or transplant?
- Are you familiar with the area surrounding your transplant center? If not, would you like to learn more about the area?
- Have you been able to meet other rehab or transplant patients?
- What rehab or transplant topics would you like to become more educated on?
- What are your hobbies? What do you like to do when you aren't in the hospital?
- What is your favorite movie or TV show?
- What type of music do you like?
- When you are in the hospital, what do you do to pass the time?
- How has COVID impacted your day-to-day life?
- Do you like to travel? Have you had the chance to travel anywhere fun?
- Do you work or did you ever work? What do/did you do?
- Do you have any pets?

Transplant Unwrapped Ambassador Leadership



Director of the Transplant Unwrapped Ambassador Program: Melinda Nelson

Melinda Nelson is a resiliency expert, life coach, and multivisceral transplant recipient. Melinda was born with Chronic Intestinal Pseudo-Obstruction Syndrome (CIPO) and spent 36 years on TPN. She is also a caregiver/mom now raising a child with the same disease.



As director of the Transplant Unwrapped Ambassadors program, Melinda helps to connect "experienced" patients/caregivers with those who are new to the intestinal world. Because she has experience being "both" the patient and a caregiver, she "truly" understands transplant, intestinal conditions, and living with a chronic illness.

Contact Information:

Email: melinda@transplantunwrapped.org

Transplant Unwrapped Ambassador Leadership

President and Founder of Transplant

Unwrapped: Kayla Pfab



Kayla is the President and Founder of Transplant Unwrapped. She has received two transplants, including an isolated intestinal transplant in November of 2015 and a modified multivisceral transplant (stomach, pancreas, duodenum, and small intestine) in February 2019. Kayla has her Bachelor's degree in Health Sciences from Duquesne University and was pursuing her Master's in Physician Assistant Studies when she became too ill and required transplantation.



Kayla has a passion for helping others and truly believes the education of both patients and clinicians can lead to better care and outcomes. Kayla currently lives in Dallas, Texas with her family. In her free time, Kayla enjoys going on long walks, baking, and traveling. Kayla helps to support and coordinate the Ambassador program. Feel free to contact her with any questions you may have about Transplant Unwrapped, intestinal failure, or intestinal and multivisceral transplant.

Contact Information:

Email: kayla@transplantunwrapped.org

Cell: (804)-516-5034

Have Questions? Contact us.

Melinda Nelson, Director Transplant
Unwrapped Ambassador Program
Email: melinda@transplantunwrapped.org

Kayla Pfab, President and Founder Transplant Unwrapped

Email: kayla@transplantunwrapped.org

Cell: (804)-516-5034

Transplant Unwrapped Information

Address: 6717 Palermo Trail, Flower

Mound, TX 75077

Email: info@transplantunwrapped.org

Website: www.transplantunwrapped.org

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