

## Post-Transplant Lymphoproliferative Disorder Externally led Patient Focused Drug Development Meeting May 4, 2022

12:30pm Welcome, Opening Remarks, and Meeting Overview

Debbie Drell, Director of Membership, NORD

Ariel Markowitz-Shulman, Associate Director of Strategic Planning, NORD

Peter Saltonstall, President & CEO, NORD

Swapna Kakani, patient advocate

12:45pm Clinical Overview of Post- Transplant Lymphoproliferative Disorder

Thomas M. Habermann, MD, Division of Hematology, Department of Medicine,

Mayo Clinic

1:00pm Welcome Remarks

Nicole Gormley, MD, Director, Division of Hematology Malignancies II, FDA

1:10pm Overview of Discussion Format & Demographic Polling Questions

Debbie Drell, Director of Membership, NORD

Ariel Markowitz-Shulman, Associate Director of Strategic Planning, NORD

1:25pm Topic 1: Living with PTLD—Burdens and Symptoms

Ellen Keyser Endelman, patient Sarah O'Connor, caregiver Marianna DeLeon, patient Rebekah Palmer, patient

Greg and Cyndi Tufaro, caregivers

1:50pm Polling Questions and Facilitated Audience Discussion on Topic 1

Debbie Drell, Director of Membership, NORD

Ariel Markowitz-Shulman, Associate Director of Strategic Planning, NORD

2:50pm Break

3:00pm Topic 2: Current & Future Treatments

Erin Tansey, caregiver Swapna Kakani, patient Brad Buchanan, patient Michelle Pfab, caregiver Ola Ojewumi, patient

3:30pm Polling Questions and Facilitated Audience Discussion on Topic 2

Debbie Drell, Director of Membership, NORD

Ariel Markowitz-Shulman, Associate Director of Strategic Planning, NORD

4:25pm Closing Remarks

Rebekah Palmer, patient

4:30pm Wrap Up and Next Steps

Debbie Drell, Director of Membership, NORD

Ariel Markowitz-Shulman, Associate Director of Strategic Planning, NORD

4:45pm Adjourn

Agenda subject to change.

