

# Creating Advocates through Research Education (CARE) Training Program

 St. Baldrick's  
FOUNDATION



TRAINING PROGRAM

# St. Baldrick's Foundation



- Volunteer and donor powered charity committed to supporting the most promising research to find cures for childhood cancers and give survivors long and healthy lives
- Largest non-government funder of childhood cancer research grants
- Signature events – Head shaving!
- Network of more than 6000 childhood cancer families
- Co-chair of the Alliance for Childhood Cancer



# CARE Training Program

- Made possible by an educational grant from Bayer HealthCare.
- Aims to train and integrate childhood cancer patients, survivors, and caregivers into the research process to ensure that the needs of childhood and young adult cancer patients and caregivers are accounted for.
- Incorporating the perspective of childhood cancer patients and caregivers into the R&D process is critical to developing treatments and cures that will allow more kids and young adults with cancer to lead long, healthy lives.
- CARE provides an overview of key terminology, concepts, and processes involved in clinical trials and drug development.

# CARE Program Structure



## CARE Advisory Committee

Felice Adler-Shohet, MD Children's Hospital of Orange County	Sarah Milberg, MPP St. Baldrick's Foundation
Kelly Faulk, MD, MSCS Children's Hospital of Colorado	Ronald Rozman Genentech/Roche
Bambi Grilley, RPh, RAC, CIP, CCRC, CCRP Baylor College of Medicine	Carlos Sandi EKG Insights
Nancy Lenfestey, MHA St. Baldrick's Foundation	Julie Wolfson, MD, MSHS Univ. of Alabama at Birmingham School of Medicine

## MODULES



1. Clinical Trials Overview



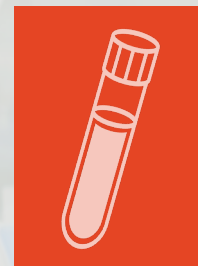
2. Institutional Approval and Initiation of Clinical Trials



3. The Drug Development and Review Process



4. The Complexities of Childhood Cancer Research



5. Biomarkers in Childhood Cancer



6. Introduction to Genomics and Personalized/Precision Medicine



7. Quality of Life and Patient-Reported Outcomes



8. Psychosocial Research and Childhood Cancer



9. Childhood Cancer Survivorship Research



10. Ethics in Pediatric Oncology



11. The Patient Advocate's Role in Scientific Review

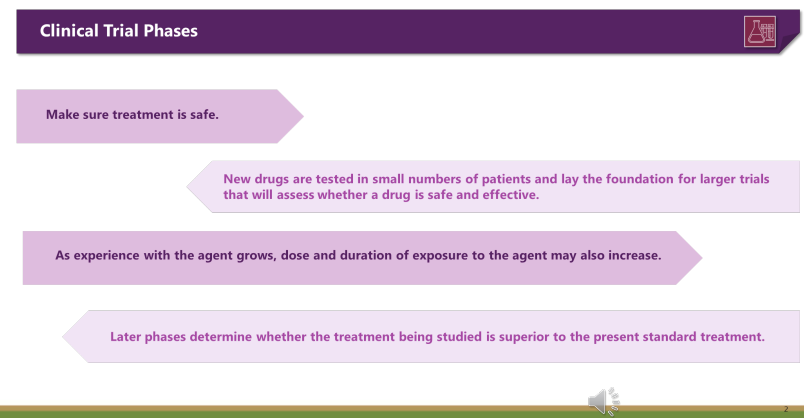
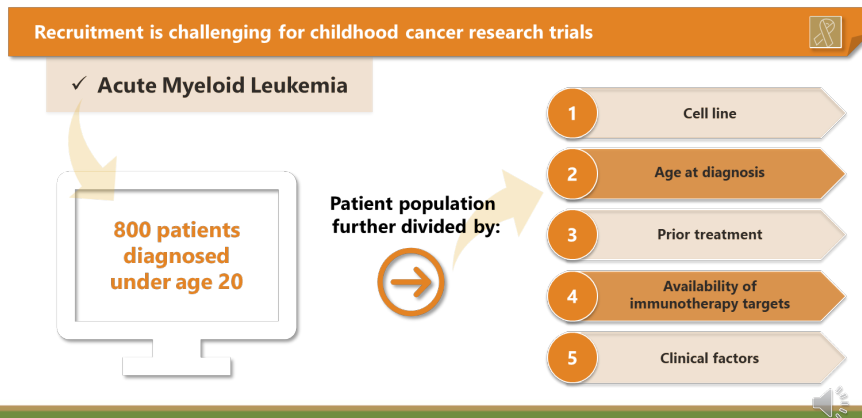


12. Advocacy

# Module Development and COVID Curveball



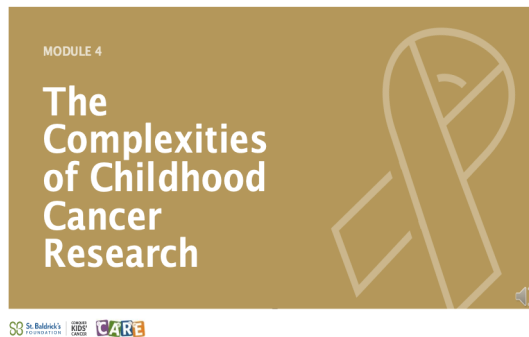
- COVID = Pivot from in-person training to a 2-pronged approach: 1) online training and 2) companion resource guide.
- How best to present information for the online training?
  - Develop slides based on Resource Guide content, develop graphics, brainstorm ideas (e.g., animation and contrasting color schemes) for making the information more “digestible.”
  - Pair slides with narration to appeal to both visual and auditory learners



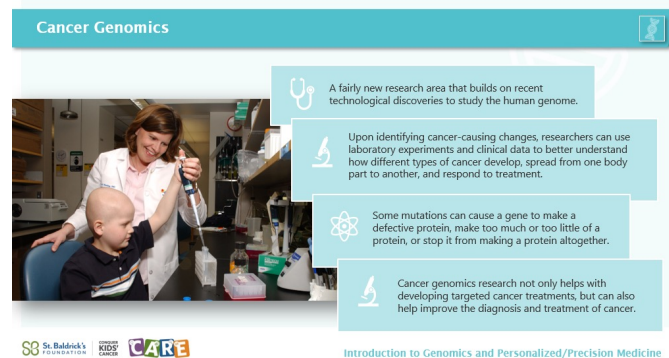
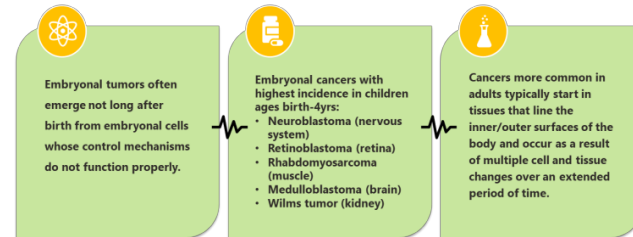
# Resource Guide Refinement + Online Training LMS



- Finalize Resource Guide: Review by a scientific writer
- Uploaded PowerPoint slides as video files into Talent LMS



Childhood cancers are often biologically different from those in adults



# CARE Training Program



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**CARE**

TRAINING PROGRAM

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RESOURCE GUIDE

Supported in part by an educational grant from Bayer HealthCare Pharmaceuticals Inc.

CARE Training Program

< MODULE 1 QUIZ > EDIT ADD FILES MORE

1-2. Which type of clinical trial/study tests new treatments or new ways to use existing treatments and is designed to answer questions regarding: safe dose of a drug; how it should be administered; whether it can help prolong the lives of people with cancer; and whether it can shrink or prevent tumors from growing and spreading to other places in the body?

- a. Prevention trial
- b. Treatment trial
- c. Screening trial
- d. Quality of life trial
- e. Natural history study

Submit answer

Question 2 of 5

## The Importance of Survivorship Research

1

Many pediatric cancer survivors experience physical, psychological, and social effects of treatment both during the administration of treatment and months to years after active therapy.

3

Some late effects can be easily identified (e.g., amputation), but others are subtle (e.g., scoliosis) or only identifiable with screening and/or imaging (e.g., infertility).

2

**Late effects** of cancer therapy are complications or side effects that emerge following the conclusion of treatment for childhood cancer and can occur anywhere in the body, including secondary cancers, heart and lung problems, infertility, anxiety and depression, and learning difficulties.

4

While some effects are temporary or improve with time, others are permanent or worsen with time and negatively impact the progression of other age-related diseases.

Childhood Cancer Survivorship Research 5



# Program Roll-Out



- Conducted testing and rolled out the program with the first cohort of advocates in November 2021.
- Initial roll-out (invitation only) with first cohort: 13 advocates  
→ refined modules → 2<sup>nd</sup> cohort: 18 advocates
- 100% of survey respondents found the training informative
  - ✓ Training is very comprehensive and easy to navigate
  - ✓ I really enjoyed the training and learning more about advocacy and the role we can play. I think it will be important to have the resource guide to fall back on over time to review.
  - ✓ Knowledge is power



Thank you!

 **St. Baldrick's**  
FOUNDATION  
*Conquer Childhood Cancers*