



CANCER AND BLOOD DISORDERS PROGRAM

# Advances in Childhood Cancer and Blood Disorders Care in Western New York: COVID-19 and the Future



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# Roswell Park Oishei Children's Cancer & Blood Disorders Program

- Only program of its kind in WNY, combining strengths of two premier specialty centers - Upstate & WNY's only NCI-designated Comprehensive Cancer Center and stand-alone children's hospital
- Allows for increased collaboration on best practices and quality assurance across continuum of pediatric cancer care – inpatient and outpatient
- Comprehensive, multidisciplinary team of specialty-trained clinicians and support staff, from physicians to nurses, patient navigators and case managers, specializing in all areas of pediatric oncology and hematology







The Katherine, Anne  
& Donna Gioia  
Pediatric Center at  
Roswell Park



ROSWELL  
PARK®

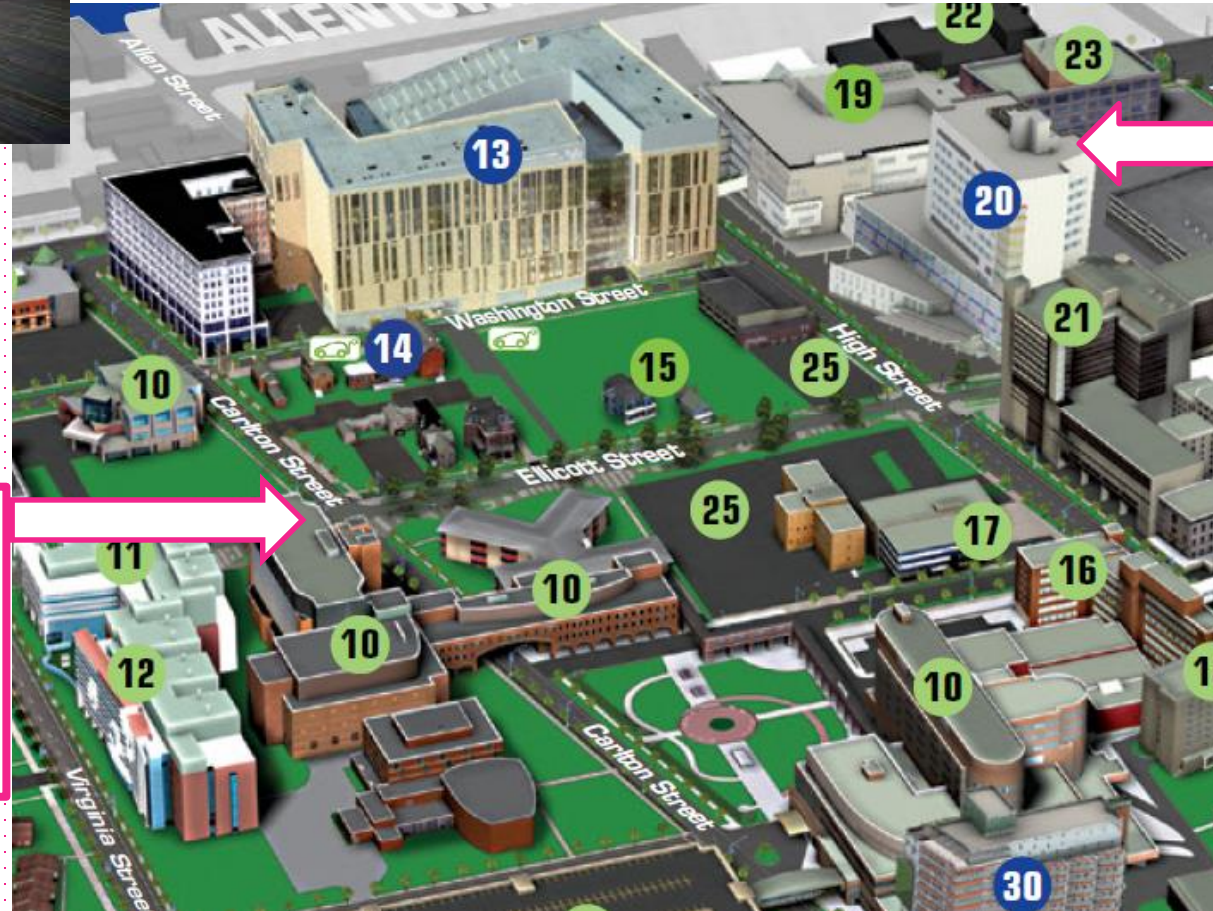


OISHEI  
Children's



## CANCER AND BLOOD DISORDERS PROGRAM

The Ralph C. Wilson, Jr.  
Hematology/Oncology  
Patient Suite at Oishei  
Children's Hospital



Inpatient  
(including  
BMT)

Opened  
November  
2017

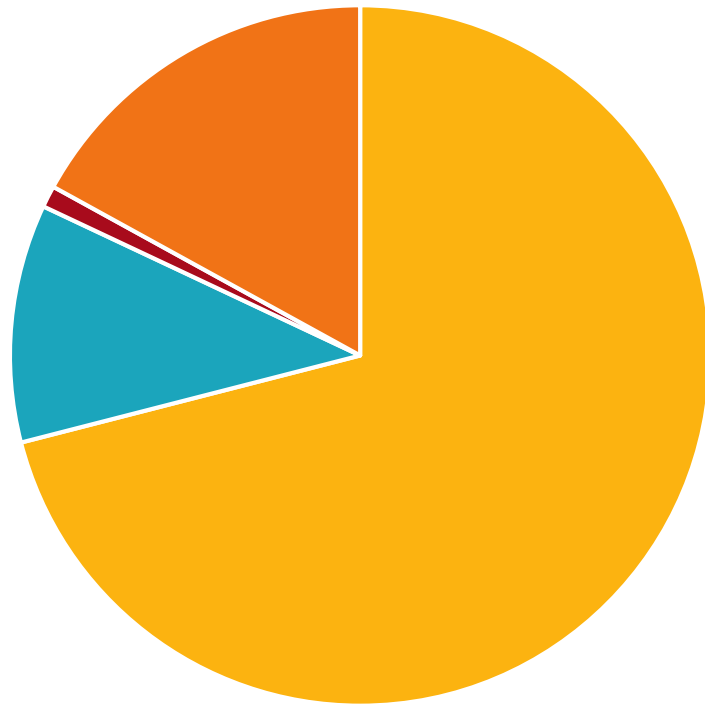
Chemo-  
therapy  
Infusion and  
Outpatient  
Center

Opened  
September  
2017



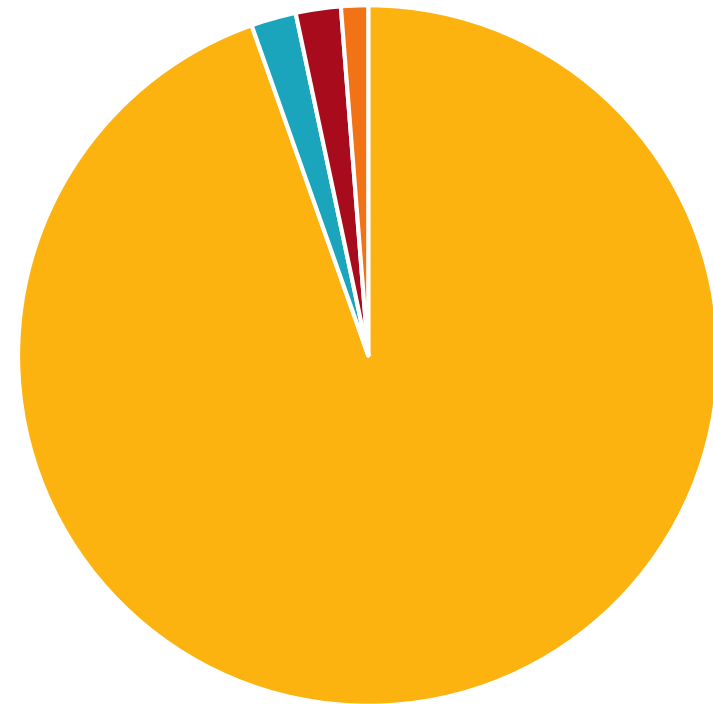
# Inpatient Discharges

2016



■ Great Lakes ■ Roswell ■ Other WNY ■ Outmigration

2019



■ Great Lakes ■ Roswell ■ Other WNY ■ Outmigration



Natasha Buxbaum



Denise Rokitka



Clare Twist



Matt Barth



Meghan Higman



Kara Kelly



Barb Bambach



Ajay Gupta



Steve Ambrusko



Beverly Schaefer



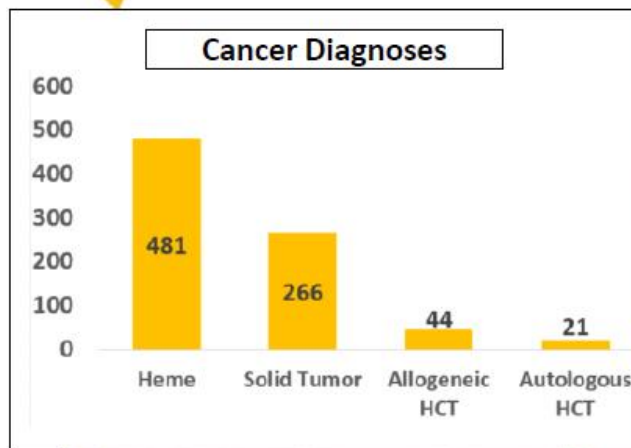
# Areas of Expertise

## **Pediatric Oncology**

- Neuroblastoma
- Sarcomas
- Brain Tumors & Neurofibromatosis
- Acute Leukemias
- Lymphomas
- Cancer Survivorship
- Young Adult Oncology
- Clinical Trials

## **Pediatric Hematology**

- Sickle Cell Anemia
- Vascular Anomalies
- Hemophilia
- Thromboses
- Adolescent Women Bleeding Disorders

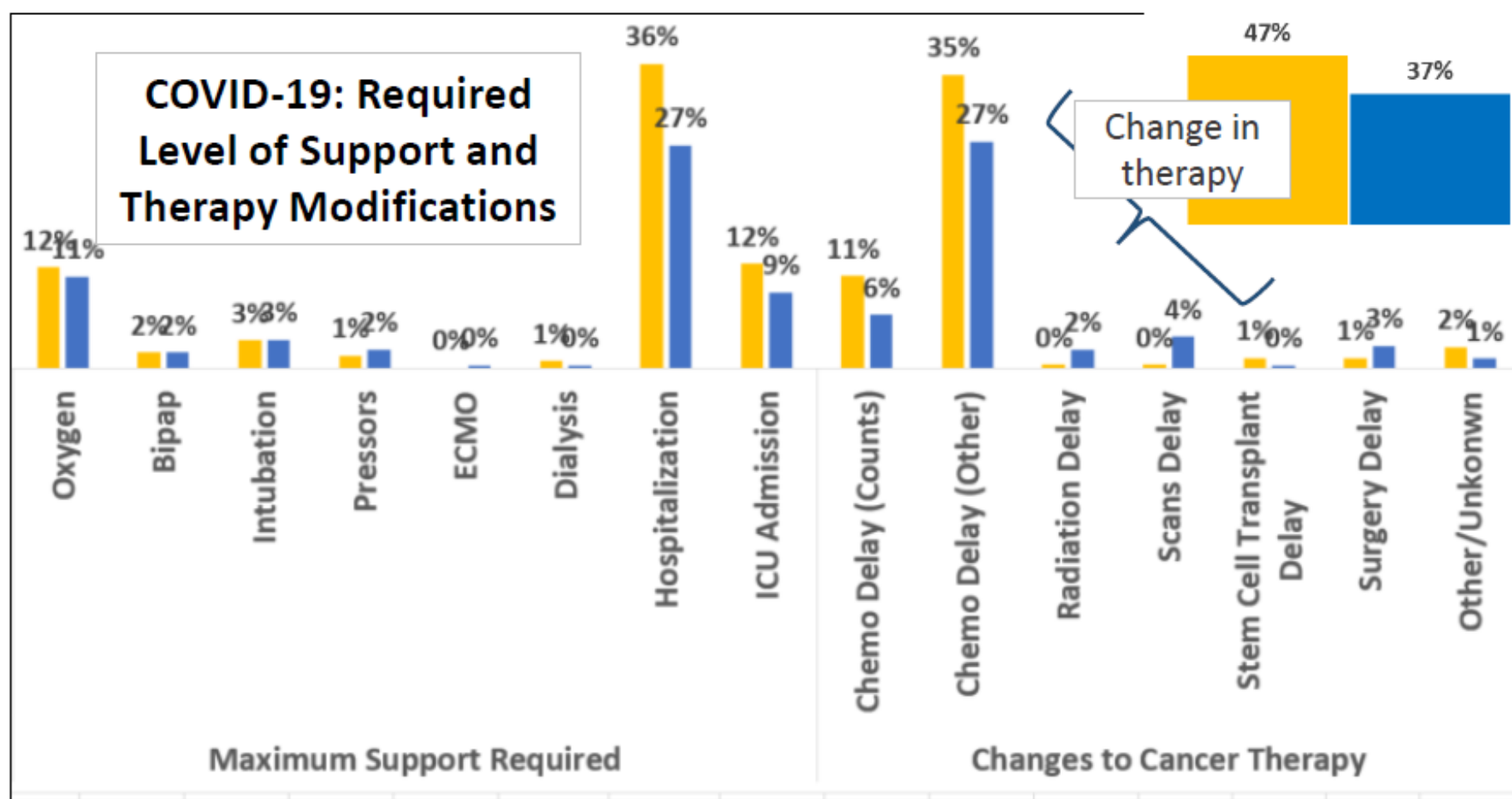


Sociodemographics		
Age: Median (Range)	12y (0-34)	
	N	%
Gender		
Female	317	42%
Race / Ethnicity		
Non-Hispanic White	247	33%
Hispanic or Latino	352	47%
Black	82	11%
Asian	27	4%
Unknown	39	5%
Insurance		
Public/Uninsured	405	59%
Private	238	32%
Other/Unknown	58	8%



Note: All cases in a state are reported in aggregate, with 1 bubble per state

\*To report cases or find previous versions of this report and FAQs, visit:  
<https://www.uab.edu/medicine/icos/icos-research/the-pocc-report>



Death (n=21, 3%)		
Age: Median (Range)	16	(1-25)
Heme	11	52%
Relapsed	11	52%
Male	12	57%
Non-Hispanic White	7	33%
Hispanic	10	47%
Public/Uninsured	13	62%

Median Symptom Duration (of Those with Symptoms)
Overall: 5d (1-60)
Heme: 5d (1-60)
Solid: 4d (1-60)

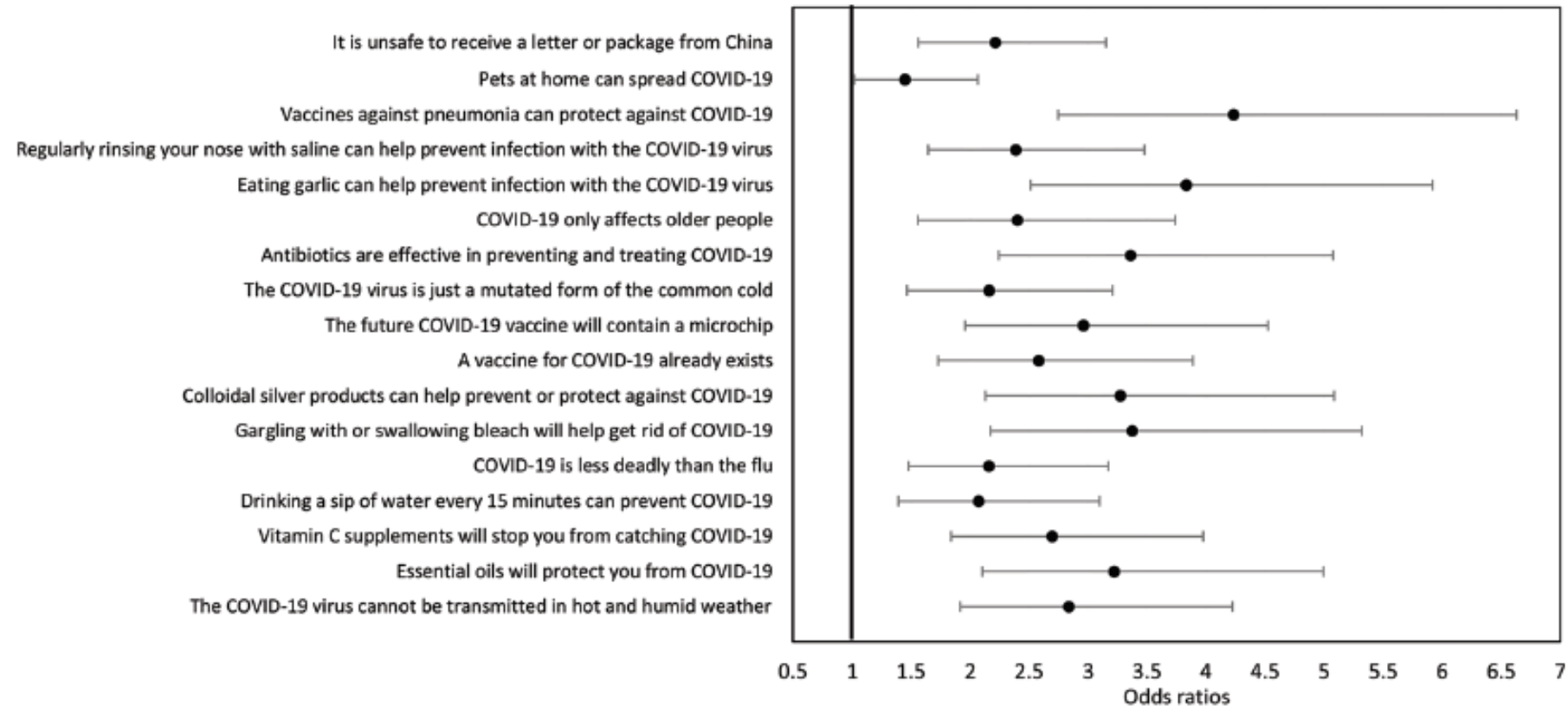
Co-Infections		
	N	%
Bacterial	31	4%
Fungal	2	0%
Viral	21	3%



# Pandemic Impact on Clinical Program

- Outpatient:
  - Infusions maintained at historical rates
  - Telemedicine Visits: Identified new opportunities – historically noncompliant, outpatient chemo monitoring
- Inpatient:
  - COVID19 related complications: Primarily Adolescents/Young Adults with Sickle Cell Disease
  - MIS-C Consultations for anticoagulation management
  - Surge in new patient diagnoses following 1<sup>st</sup> wave in June
  - “Elective” BMTs postponed during 1<sup>st</sup> wave

# COVID-19 Related Misinformation among Parents of Children with Cancer



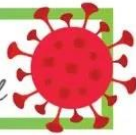
**Figure.** Forest plot of odds ratios for parents of children with cancer (as opposed to parents of children without cancer) predicting each dichotomized COVID-19 misinformation item ("definitely true" and "likely true" answers coded as 1, others as 0). Results are adjusted for sex, age, race, and education of parent as well as COVID-19–related stress. COVID-19, coronavirus disease.

# Resources for Children



ROSSELL PARK COMPREHENSIVE CANCER CENTER

## COVID-19 AND YOUR CHILD: *Coping Tips to Help Navigate the New Normal*



### NEW NORMAL

With the presence of the Coronavirus in society, all of our lives have had to change, including your child's. If they are struggling to accept what is going on or if you are looking for some ways to help them understand, here are some tips on coping with COVID-19.



We recognize that this is a very difficult time for everyone. The psychosocial team, consisting of social workers, child life specialists, and psychologists, is here to help you. Reach out to a psychosocial team member with any questions or concerns you may have.

### TIPS FOR YOUR INFANT OR TODDLER (under 6)



**Be Consistent**  
Routine is incredibly important for children at this age. Keeping a routine helps their mind and body know what to expect.



**Introduce Them to a Face Mask**  
When coming in for treatment and checkups, our staff will be wearing face masks. Get your child used to seeing people wearing them by playing peek-a-boo with a mask to help your child adjust.



**Make Time for Yourself**  
Make sure you're taking time for yourself and meeting your own emotional needs. Children can often sense caregivers' distress so it's important for you to model good self-care.



**Take a Breath**  
Teach your toddler about calming their own body by using simple language and activities. For example, practice deep breathing through blowing bubbles or blowing a pinwheel.



**Have Some Fun**  
Make required activities, like washing hands, fun and silly through play, singing and dancing.



1-800-ROSSELL (1-800-767-9355) | RoswellPark.org



ROSSELL PARK COMPREHENSIVE CANCER CENTER

## COVID-19 AND YOUR CHILD: *Coping Tips to Help Navigate the New Normal*



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### TIPS FOR YOUR CHILD (6-11)



**Be Consistent**  
Routine is incredibly important for children at this age. Keeping a routine helps their mind and body know what to expect.



**Get Active**  
Have a time set up for activities that get them moving and their heart rate up, like running, jumping rope, or playing a sport in the backyard. This not only gets them moving but will improve their mood.



**Feel the Feelings**  
Validate your child's feelings and reassure them that it's okay to be feeling whatever they feel – whether that's happiness, sadness, anger or frustration. Communicate that they are experiencing a lot of changes and strong emotions, and that it is okay!



**Get Creative**  
Desensitize them to their required face masks by allowing them to decorate their own. Allowing them to personalize it will also give them a feeling of control over the situation.

### Talk It Out

Be open and honest with your child about what is going on and explain it in a way they will understand. For example, you could say something like, "Coronavirus, which you may hear also being called COVID-19, is a germ that can travel from person to person through things like sneezing or coughing. This virus can make a person really sick. This is why we need to wear a mask when outside the house, wash our hands often, and keep a safe distance from other people."

### Empower Them to Help Out

Elementary and middle schoolers like to feel in control of their environment. Empower them to help the community by writing letters to frontline workers, cutting out hearts to place in windows, drawing encouraging chalk messages on the sidewalk or baking goodies for someone in need.

### Teach Self Love

Educate them on the importance of self care and healthy coping mechanisms. Don't forget to help create a space in their busy schedule for them to practice!

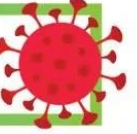


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ROSSELL PARK COMPREHENSIVE CANCER CENTER

## COVID-19 AND YOUR TEEN: *Coping Tips to Help Navigate the New Normal*



### NEW NORMAL

With the presence of the Coronavirus in society, all of our lives have had to change, including your child's. If they are struggling to accept what is going on or if you are looking for some ways to help them understand, here are some tips on coping with COVID-19.



We recognize that this is a very difficult time for everyone. The psychosocial team, consisting of social workers, child life specialists, and psychologists, is here to help you. Reach out to a psychosocial team member with any questions or concerns you may have.

### TIPS FOR YOUR ADOLESCENT (12-18)



**Be Consistent**  
Routine is incredibly important to adolescents. Keeping a routine helps their mind and body know what to expect.



**Talk It Out**  
Have an open and honest discussion about what is going on in the world and how it affects them directly.



**Be a Team**  
Let them know that you are all on the same team! That means doing everything they can do help keep you and others safe.



**Listen to Their Emotions**  
Validate their feelings and let them know it's okay to feel whatever it is they're feeling. Be on their side – acknowledge all the changes they are experiencing.



**Empower Them**  
Help them make good out of a really difficult experience by encouraging and believing in the efforts they are making.



**Allow Tech Time**  
Technology is a great way for them to connect to friends while they can't be together. Allow appropriate use of devices for them to chat with peers.



**Teach Self Love**  
Educate them on the importance of self-care and healthy coping mechanisms. Don't forget to help create a space in their busy schedule for them to practice!



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DOI: 10.1002/pbc.28409

## **SPECIAL REPORT**



# **The COVID-19 pandemic: A rapid global response for children with cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI, and St Jude Global**

## **COVID-19 and Hodgkin Lymphoma: Frequently Asked Questions**

(Version 5.0; last updated February 5, 2021)

*Input from Ranjana Advani, MD; Nancy Bartlett, MD; Ann LaCasce, MD, MSc; Leo Gordon, MD; Kara Kelly, MD; Peter Johnson, MD, FRCP; Kerry Joanne Savage, BSc, MD, MSc; Laurie Sehn, MD, MPH; and Jane Winter, MD.*

Note: Please review **ASH's disclaimer** regarding the use of the following information.



Contents lists available at [ScienceDirect](#)

## **Progress in Pediatric Cardiology**

journal homepage: [www.elsevier.com/locate/ppedcard](http://www.elsevier.com/locate/ppedcard)



### **Editorial**

COVID-19 associated Multisystem Inflammatory Syndrome in Children (MIS-C) guidelines; a Western New York approach

Received: 10 June 2020 | Revised: 13 December 2020 | Accepted: 14 December 2020

DOI: 10.1002/pbc.28874

## **LETTER TO THE EDITOR**



## **Acute hepatic encephalopathy and multiorgan failure in sickle cell disease and COVID-19**



— IN 2015 —

THERE WERE AN ESTIMATED

**429,000**  
**SURVIVORS**

OF CHILDHOOD CANCER\*  
IN THE UNITED STATES

\*People diagnosed with cancer at ages 0-19 years

Source: SEER Cancer Statistics Review 1975-2015

[cancer.gov/childhood](https://cancer.gov/childhood)



Worldwide, a child is diagnosed with cancer every

# 3 MINUTES

The causes of most childhood cancers are unknown.  
At present, childhood cancer cannot be prevented.

# 80%

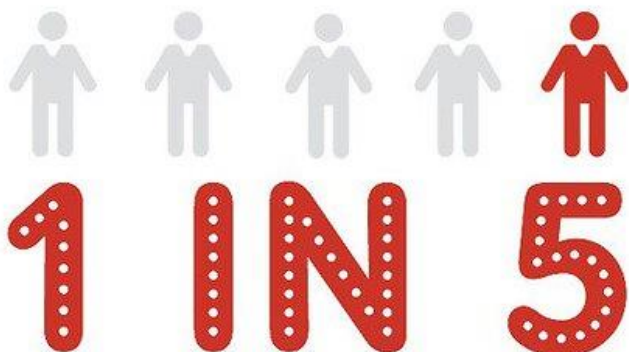


Of children are 5 year survivors.



## BECAUSE OF RESEARCH

THE CANCER DEATH RATE  
HAS DROPPED MORE  
DRAMATICALLY FOR  
CHILDREN THAN FOR ANY  
OTHER AGE GROUP.



CHILDREN DIAGNOSED WITH  
CANCER WILL DIE WITHIN 5-YEARS.

THE INCIDENCE OF INVASIVE  
PEDIATRIC CANCERS IS UP

# 29%

IN THE PAST 20 YEARS.

## 3 OUT OF 5



CHILDREN DIAGNOSED  
WITH CANCER SUFFER  
FROM LONG-TERM OR  
LATE ONSET SIDE EFFECTS.



In 20 years the FDA has  
initially approved only

## 2 DRUGS

for any childhood cancer.

# 1/2

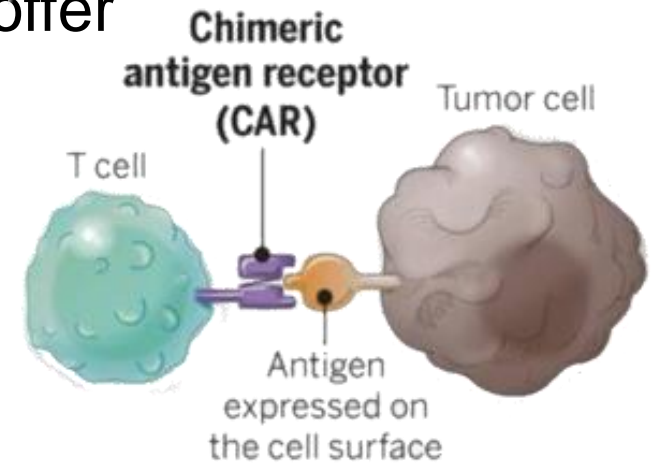
of all chemotherapies used for  
children's cancers are over  
**25 years old.**

# New Programs

- Expanded Stem Cell Transplant and Cellular Therapies Program
- Experimental Therapeutics Program
- Comprehensive Molecular Testing

# Chimeric Antigen Receptor T-cells (CAR-T)

- **Kymriah® (tisagenlecleucel)**
  - Approved by FDA August 2017 for relapsed/refractory pediatric ALL
  - Roswell Park selected by Novartis to be one of the 1<sup>st</sup> Kymriah® treatment centers in US (and only one in Upstate NY)
- **Hodgkin Lymphoma: CD30 CAR**
  - One of only about 5 pediatric programs nationally to offer
- **Solid Tumors: NY-ESO1 CAR**
  - Derived from Roswell Park Research
  - Only program nationally to offer





# NY-ESO-1 CAR-T Trial

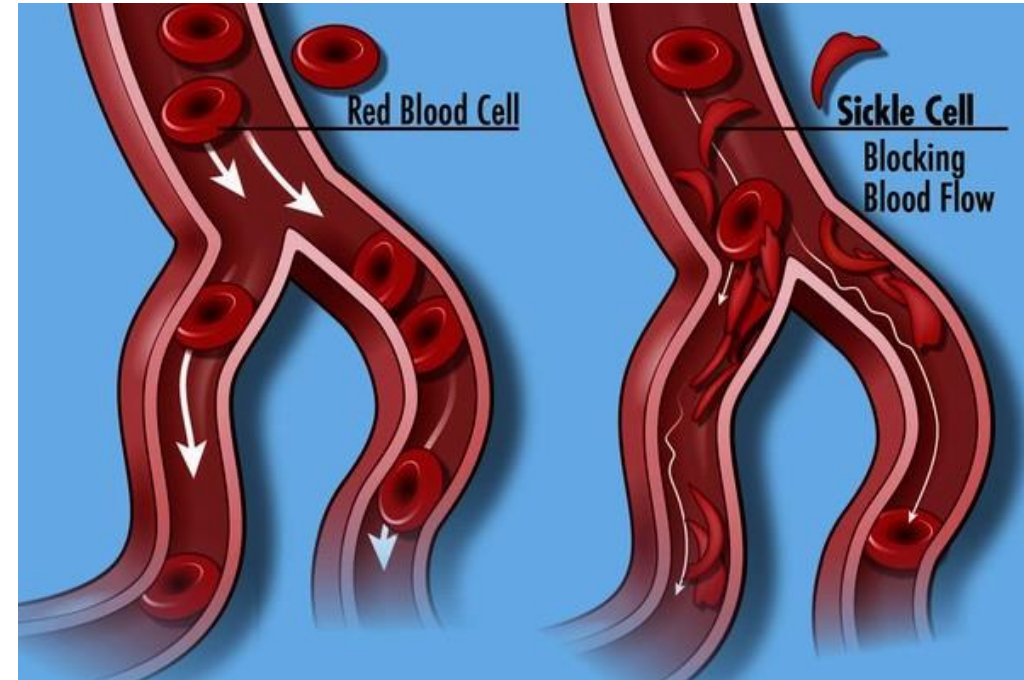
- Member of Cancer-testis antigen family genes
  - Generally expressed embryonically but can be re-expressed in a range of malignancies including pediatric solid tumors - osteosarcoma, synovial sarcoma, rhabdomyosarcoma, and neuroblastoma.
- T-cells vs NY-ESO-1 are associated with clinical responses in patients with melanoma and synovial sarcoma
- Incorporating dominant-negative TGF $\beta$  receptor II into NY-ESO-1 TCR retroviral vector used to transduce patient T cells renders these effector cells insensitive to TGF $\beta$ , enhancing their immune function
- Pediatric trial based on Roswell Park active trial in adults with advanced malignancies which currently includes adolescent patients

## **A Phase I/IIa Study to Determine the Safety and Efficacy of TGF $\beta$ Blockade in TCR-Engineered T-cell Immunotherapy in Children with Relapsed or Refractory Solid Tumors**

- Ages 1 to 18 years with relapsed/refractory pediatric solid tumor
- HLA-A\*0201 (HLA-A2.1) positive
- Decitabine plus Cyclophosphamide +/- Fludarabine
- Correlative studies analyzing gene expression and DNA methylation profiling

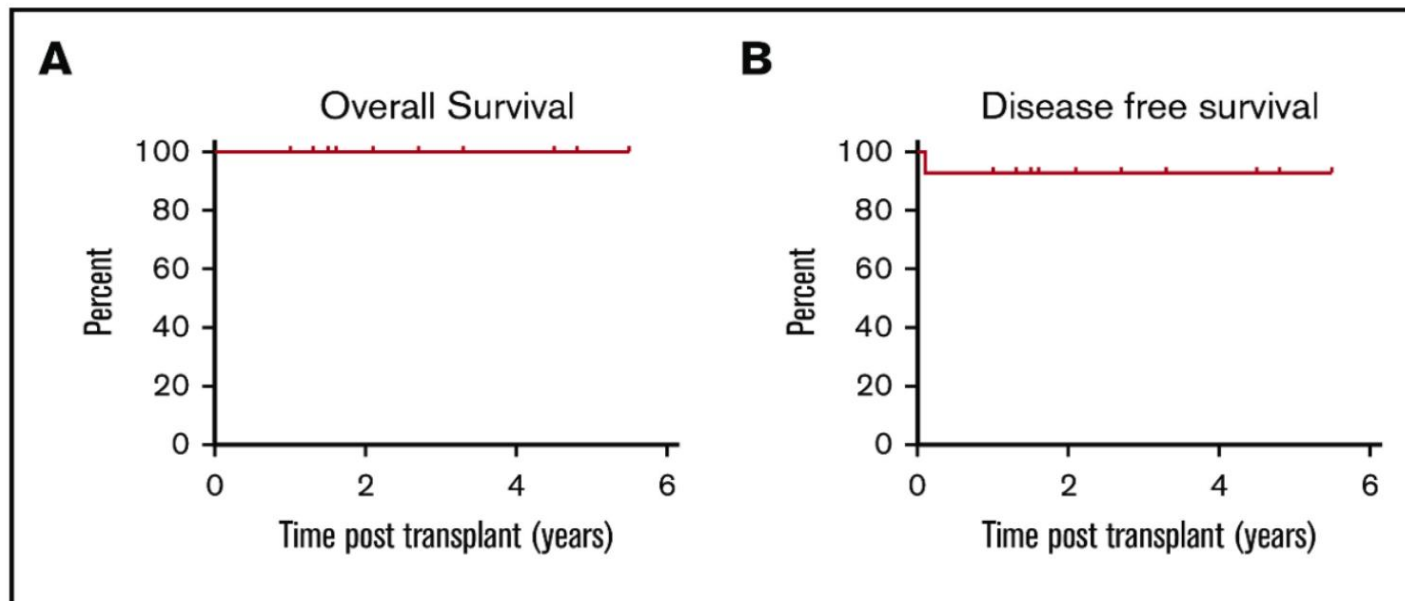
# Bone Marrow Transplant for Sickle Cell Disease

- Most common inherited blood disorder in the US
- Effects every organ/tissue in body :
  - Pain crises
  - Strokes, silent infarcts
  - Acute chest, pulmonary HTN
  - Avascular necrosis
  - Retinopathy
  - Renal failure
- Median survival = 40 years
- New Transplant Protocols for Unrelated Donors, Haploidentical Donors



# Unrelated Donor for Sickle Cell

- Abatacept is effective as GVHD prophylaxis in unrelated donor stem cell transplantation for children with severe sickle cell disease Blood Advances 2020 Aug 25; 4(16): 3894-3899



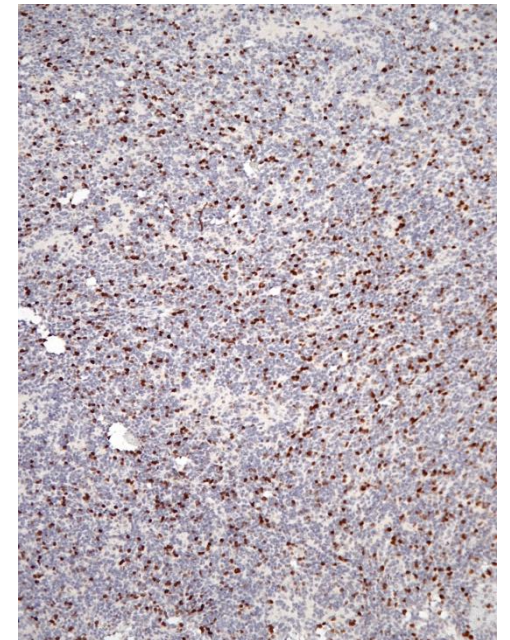
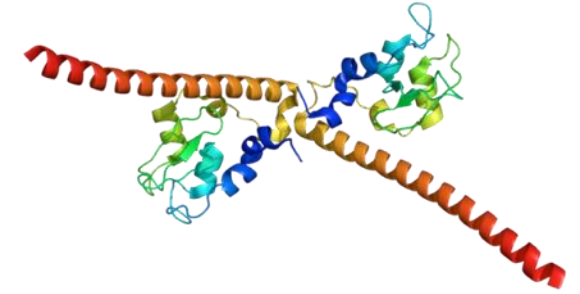
14 sickle cell pts-7 MUD, 7MMUD  
Gr 2-4 aGVHD: 28.6%  
Gr 3-4 aGVHD: 7%  
cGVHD @ 1yr: 57%- all limited/mild except 1

ASCENT trial: 4 additional doses Abatacept at Days +56, +84, +112, +150

# SurVaxM: A Survivin-Targeted Immunogen

## Survivin

- Common oncofetal antigen (Inhibitor of Apoptosis Antigen)
- Highly expressed in many cancer types, including pediatric brain tumors
- Downregulation is lethal to the tumor
- SurVaxM Tumor Vaccine (Peptide Mimic)
  - Stimulates a potent immune response
  - Cross-reacts to wild type survivin in tumor cells

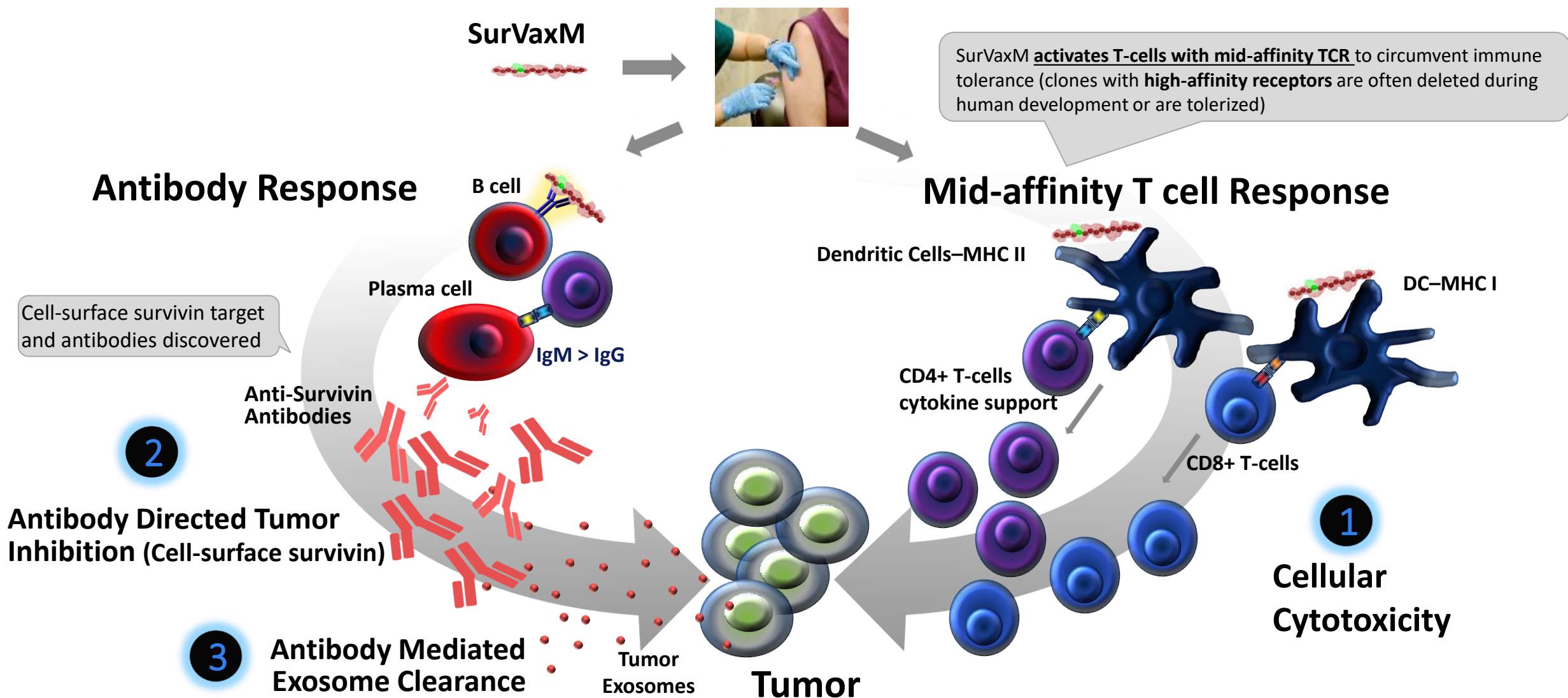




# SurVaxM: Multiple Mechanisms of Action

## Dosing Schedule

- Prime-boost dose biweekly x 4 doses
- Maintenance doses every 2-3 mos



# **PBTC-060: A Pilot Study of Safety, Tolerability, and Immunological Effects of SurVaxM in Pediatric Patients with Progressive or Relapsed Medulloblastoma, High Grade Glioma, Ependymoma and Newly Diagnosed Diffuse Intrinsic Pontine Glioma**

- **Histologic Dx:** Relapsed or progressive medulloblastoma, HGG, Ependymoma
- DIPG (no bx required) – new Dx, following radiotherapy SOC

- **Objectives:**

- Toxicity profile
- Immune correlative studies
- Comparison of 2 response criteria systems
- Efficacy, PFS/OS in the context of a pilot study

The trial will be conducted through the NCI-sponsored Pediatric Brain Tumor Consortium which includes 16 sites across North America and is targeted to open in early 2022.

- **3 Cohorts by age & Dx**

- Cohort A = age  $\geq 10$  yrs –  $\leq 21$  yrs, relapsed Medullo/HGG/ependymoma (n=12 pts)
- Cohort B = age  $\geq 1$  yrs –  $< 10$  yrs, Medullo/HGG/ependymoma (n=12 pts)
- Cohort C = age  $\geq 1$  yrs –  $\leq 21$  yrs, DIPG (n=6 pts)

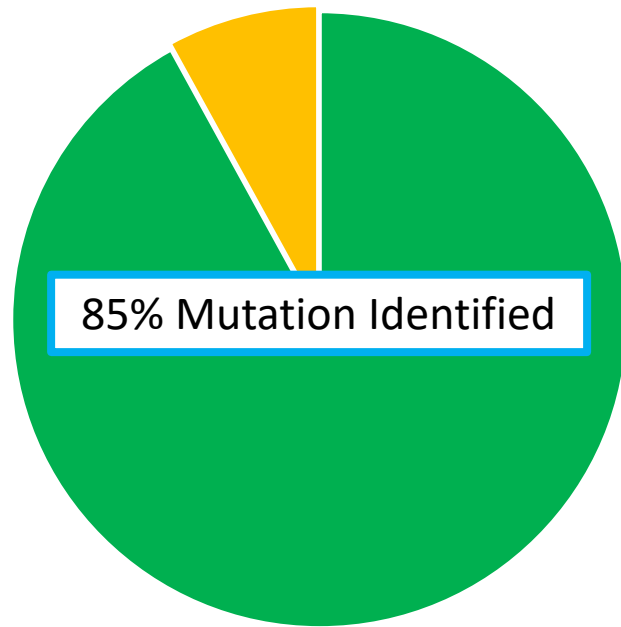
- **SurVaxM-Montanide Emulsion Administration**

- Dose: 500 mcg SurVaxM emulsion with Montanide ISA 51 sub Q + GM-CSF subQ at separate site
- Priming Phase administration schedule: 4 doses given every 2 weeks
- Maintenance Phase: Beginning 8 weeks after the fourth priming dose, a maintenance dose of SurVaxM may be given every 8 weeks ( $\pm 2$  weeks) until an off-treatment criterion is met (PD or RLT)

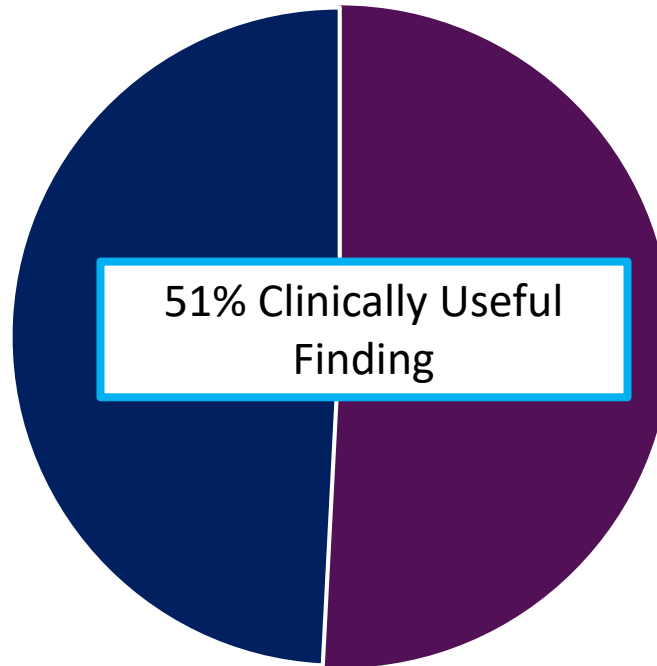


# Results to Date

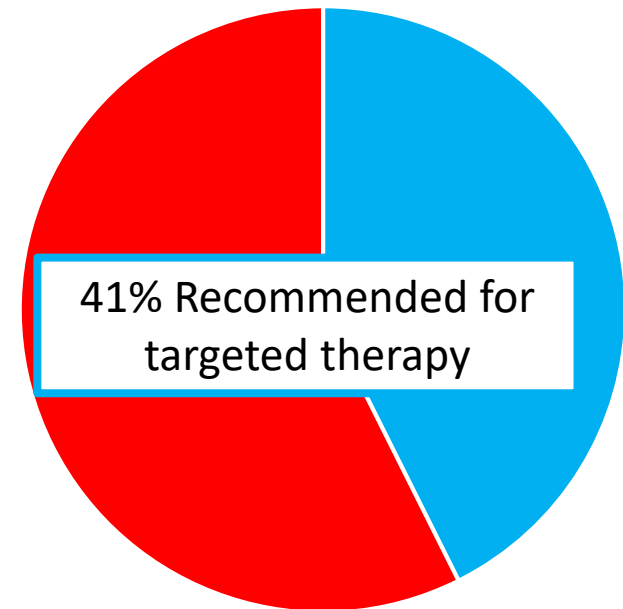
n=61



■ Mutation Identified  
■ No mutation



■ Clinically Useful  
■ Mutation with Unknown Significance



■ Targetable Mutation  
■ No Targetable Mutation



# Patient Access

- Pediatric Hematology/Oncology - (716) 845-4447
- New Patient Appointments: [1-800-ROSWELL \(1-800-767-9355\)](tel:1-800-ROSWELL)
  - New appointments  $\leq$  5 days
- Virtual Telemedicine Visits are Available
- Emergency Care:
  - Weekdays – Roswell Park Pediatric Ambulatory Center
  - Non-business Hours – OCH Emergency Department