



Taking the show on the Road

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Pediatric Cancers Overview

- Among children and adolescents (ages 0-19) in the United States, the most common types of cancer are (1) leukemias, (2) brain and CNS tumors, and (3) lymphomas
- Survival rates have improved dramatically. Five-year survival in children and adolescents in the US was:
 - In the mid-1970s: 58% of children and 68% of adolescents
 - In 2008–2014: **85% of children and 85% of adolescents**
- As of January 1, 2015 approximately 429,000 survivors of childhood and adolescent cancer were alive in the United States

MSK Kids treats by Disease

Primary Services

- Sarcoma
- Neuroblastoma
- Neuro Oncology
- Hematologic Malignancies
- Stem Cell Therapy and Transplant
- Surgery

Supportive Services

- Rehabilitation
- Long Term Follow Up
- Integrative Medicine
- Psychiatry
- Gastroenterology
- Pain and Palliative Supportive Care
- Clinical Genetics

We treat the whole patient

ChildLife
Ronald McDonald Housing
Social Work
Nutrition
Integrative Medicine

Individualized care

flexible, individual care settings that take the needs of the child family into account

Family centered care

“ Family centered care (FCC), a process of health-care delivery that emphasizes sharing of information, supporting parents in the decision-making process, and respecting the choices made by families This alliance between medical providers and the patient's family is also adaptable to respect religious, cultural, and socio-economic differences” .

Evolution of outpatient pediatrics at MSKCC

1969 PDH
Opens

2016
PACC

2019 MSK
KIDS

2022 MSK
KIDS, SCC

Meet the Regional Staff

Dedicated Pediatric RNs

Trained Patient Care Technician

Patient Care Coordinators

Nurse Practitioners

Supporting staff in the PACC

Onboarding and Ongoing training

Newly hired staff spend time in the PACC



Pediatric educator involvement



CNS involvement



Joint RRR involvement



Debrief

Seamless collaboration

Combined virtual visit

E-consents

Opportunity to participate in team meetings

Social worker

Child Life

Nutrition

Pharmacy

Psycho-oncology Service

What can be done in the regionals

Chemotherapy and immunotherapy

Radiation

Lab

Vital sign/ height and weight

Scans

Follow up visits

Regional guidelines

Centers

	Patients \geq 18 years		Patients 5 - 18 years		Patients 0 - 5 years	
	Pediatric NP or Family NP or Pediatric MD	APHON RN	Pediatric NP or Family NP or Pediatric MD	APHON RN	Pediatric NP or Family NP or Pediatric MD	APHON RN
Lab blood draw	No	No	No	No	Yes	No
Radiology - No contrast	No	No	No	No	Yes	No
Radiology - Contrast	No	No	No	No	Yes	No
Medication infusion non-chemotherapy	No	No	Yes	No	Yes	No
Low Risk chemotherapy Ex. Vincristine - irinotecan	No	No	Yes	Yes	Yes	Yes
Chemotherapy other	No	No	Yes	Yes	Yes	Yes

Child Life

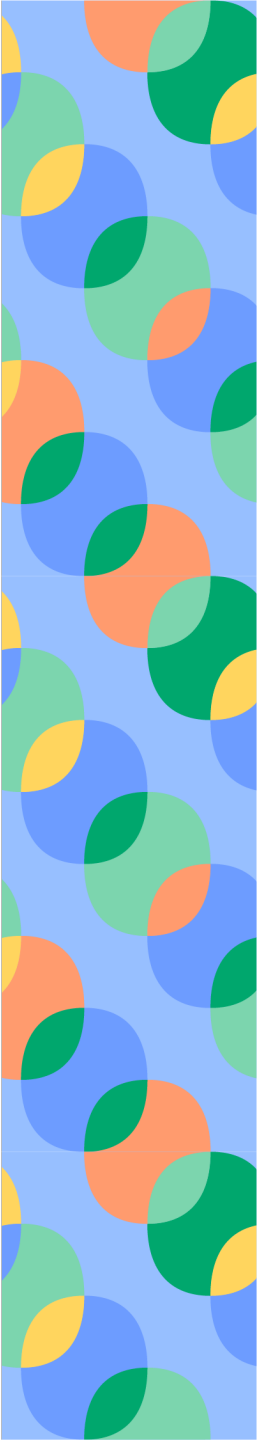
Each regional is assigned a child life point person

Prize boxes

Arts and Craft

Birthday in a box

End of treatment recognition



What is Not Available in the Regional

No sedated scans

First time administration of any new drug that has high probability of reaction

Needing child life assistance for access and blood draws

Physical therapy visit in children < 18yr

Echocardiograms

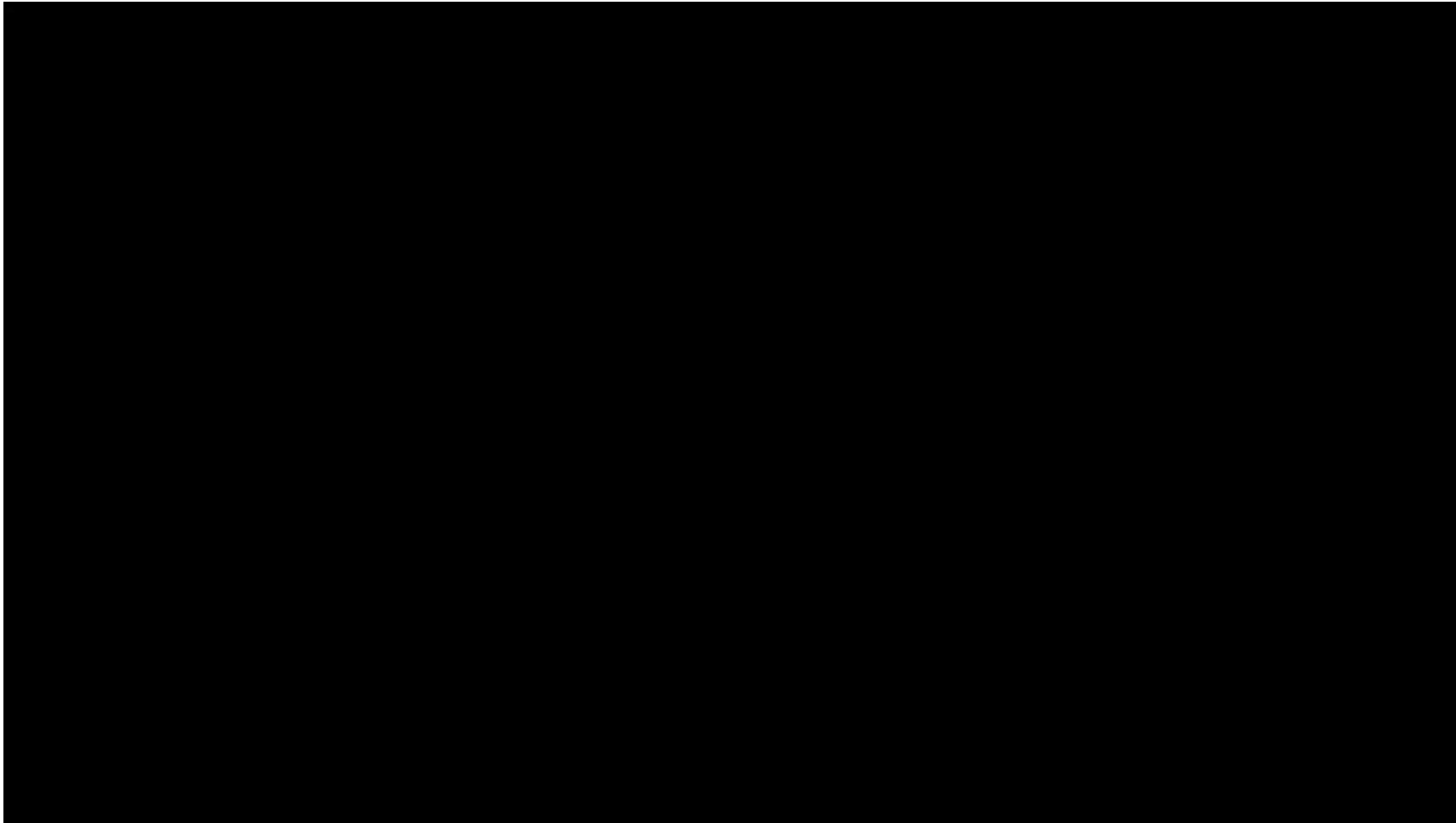
Audiograms

Dental

First time scans with contrast

Hear from our Vice Chair, Dr. Paul Meyers

Dr Paul Meyers



Long Term Survivor Clinic

Survivors of childhood cancer must continue follow-up care in adulthood to identify and treat current or potential medical, psychological, and social late effects of cancer treatment and to promote general health

Adolescent and Young Adults (AYA)

Although overall cancer cases are declining, they are on the rise in adolescents and young adults ages 15 to 39. A staggering 90,000 new cases are projected this year alone in the United States. Memorial Sloan Kettering Cancer Center is already at the forefront in this field, treating about 5,500 of these younger patients each year

The Stuart Center

Symptom Care Clinic

- New initiative serving age 12 and up
 - Presently in New Jersey only
 - Same day appointment
 - Staffed by Peds APP if on site
- Planned expansion

SCC in the Regionals

Symptom	PACC	SCC	Partner ED	Closest ED
Influenza like illness	X	X		
Ophtho - ENT infections Conjunctivitis URI, Pharyngitis, Otitis	X	X		
Hypertension	X	X		
Simple wound infection	X	X		
Mucositis	X	X		
Cellulitis/Rash	X	X		
Nausea/Vomiting	X	X		
Dehydration	X	X		
Abdominal Pain/Diarrhea/Constipation	X	X		
Urinary Problems	X	X		
Headache	X	X		
Catheter Management	X	X		
Pain Management-Outpatient	X	X		
End of Life Care	X (admit)	X (OP)		
Stable Fever non neutropenic	X	X	X	
Stable Fever neutropenic	X		X	X
Bleeding, moderate to severe petechia, bruising	X		X	X
Neurosensory/Motor-sensory loss, paresthesia, weakness, and or loss of function	X		X	X
Seizures	X		X	X
Acute shortness of breath	X		X	X

Parental Stress

For parents of children with cancer, several subdomain of stressors have been identified.

- 1) daily/role functioning (paying bills and family expenses, concerns about my job or my spouse/partner's job, having less time and energy for my other children and/or spouse);
- 2) cancer communication (talking with my child about cancer, talking to my other children, family, and friends about cancer, understanding information about cancer and medical treatment, arguing with my child about taking medicines and other treatment);
- 3) cancer caregiving (not being able to help my child feel better, the effects of my child's treatment, not knowing if my child's cancer will get better)

Financial cost

Indirect cost of cancer

Parking Hospital bill

Pharmacy cost

durable medical treatment

Direct cost

Hospital bill

Pharmacy cost

durable medical treatment

Financial Toxicity

Families of children with cancer contend with not only with the emotional burden of their child's illness but also with the distress of financial and logistical hurdles to care

Parental stressors

Parents administer medication, monitor for treatment side effects, travel back and forth from the hospital for medical care, and provide emotional support for the child with cancer and other family members. At the same time, parents must continue to financially provide for their family and accomplish day to day activities

Life disruption

Missed school

Missed work

Disruption in family life

Family scheduling

Patient Satisfaction

“Being cared for at Nassau allowed me to drop my son off at school , be there during my daughter treatment and home in time to pick him up from the bus”

“ We love all the seeing the same provider and nurses”

“ Allowed him to continue to be on the baseball team, being at a regional makes all the difference ”

Ericksons stages of Development

industry versus
inferiority

- School age

Identity versus
role confusion

- Adolescent

Intimacy versus
isolation

- Young Adults

Palliative care

The primary goal of pediatric palliative care (PPC) is to improve or maintain the best possible quality of life (QoL) for the child and their family.

Acknowledge that while receiving palliative care many are actively living and the need to provide support and resources

A review of the literature demonstrated that palliative care at home improves if there is active communication and collaboration between family, homecare and hospital

Hospice

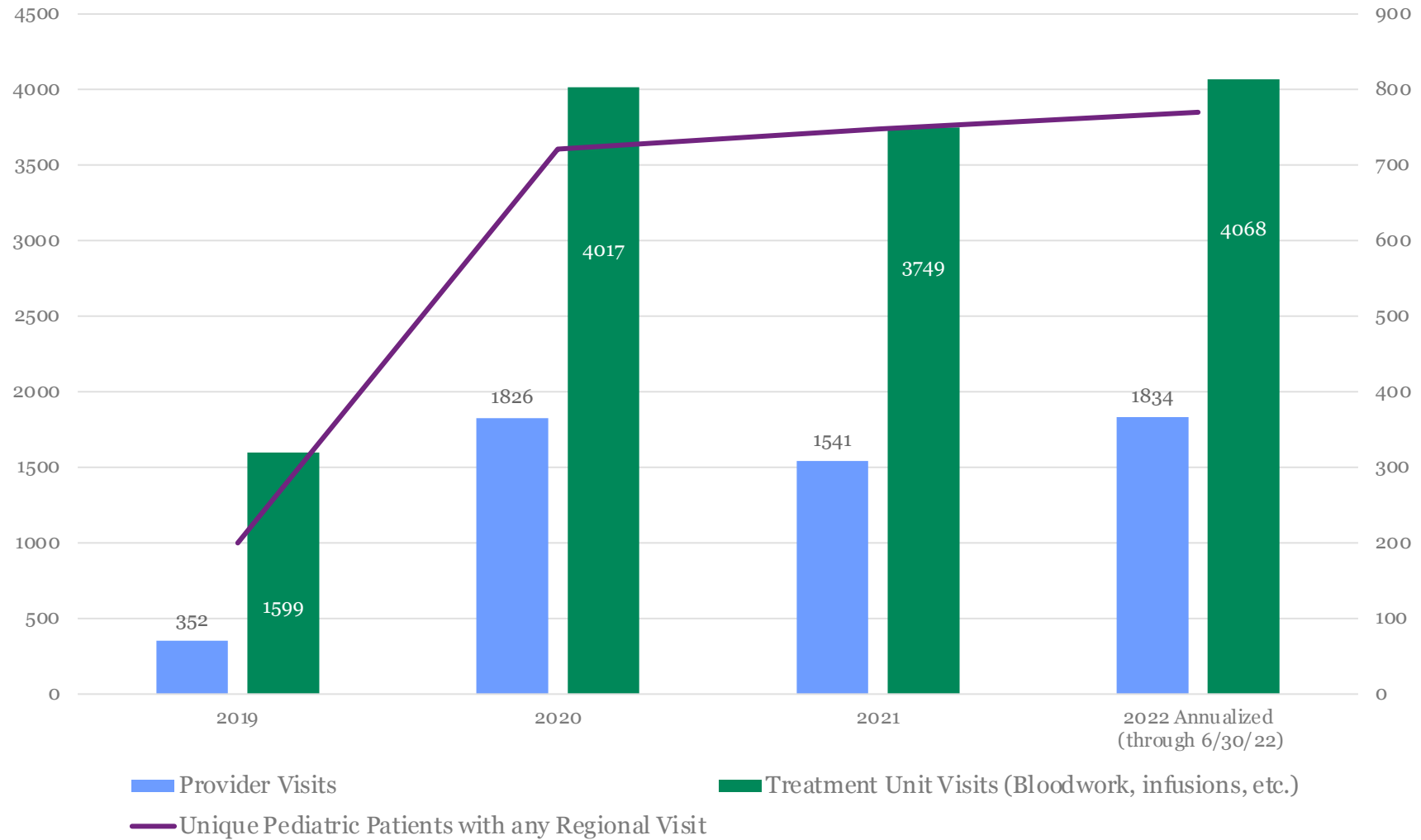
Pediatric hospice can serve as an “add-on” to existing medical care, allowing patients to continue with curative treatments. This is called “concurrent care.”

Consistency

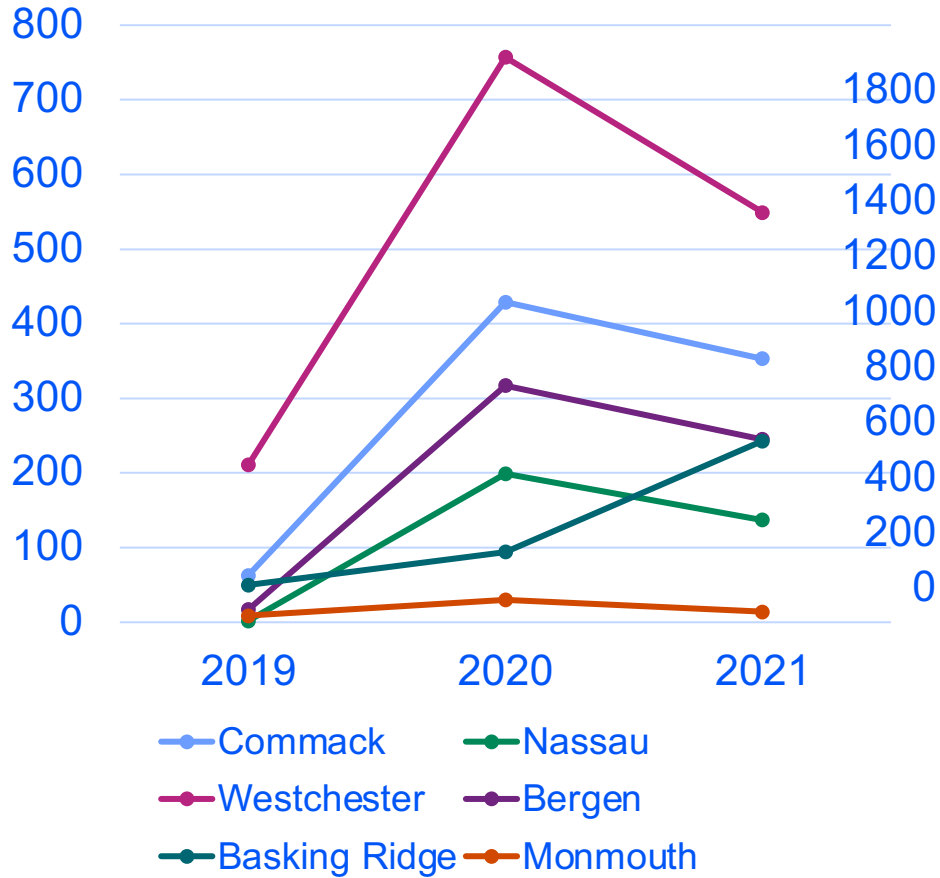
Consistency in care allows for high-quality communication is associated with parental peace of mind, feelings of being acknowledged and comforted, and greater trust in the provider.

Increased Access to care

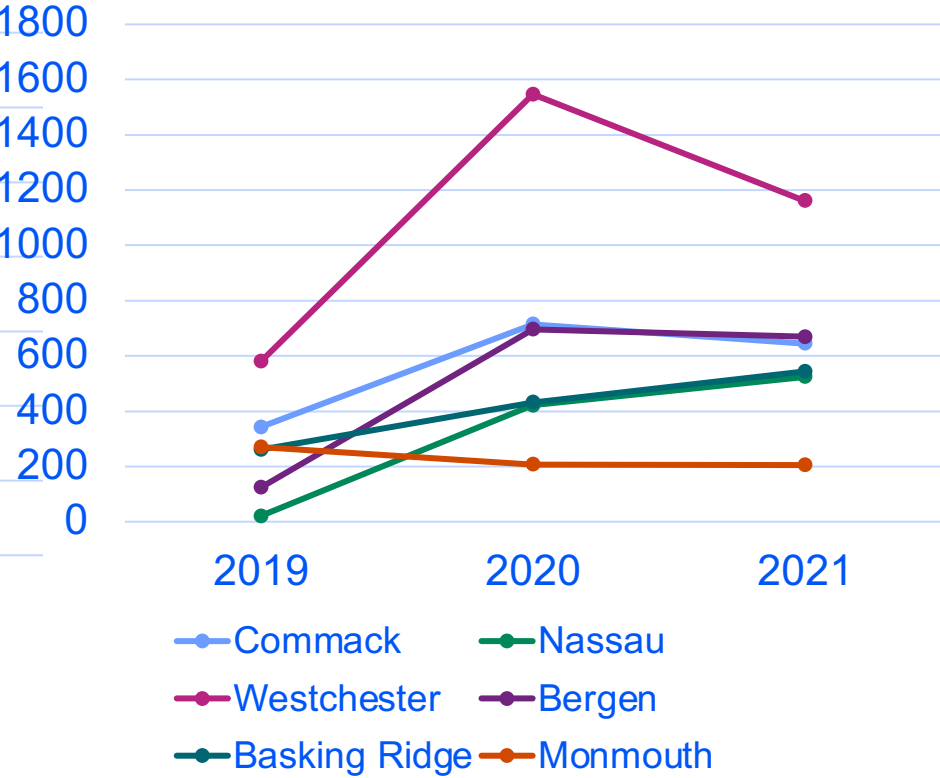
Pediatric Outpatient Activity in Regional Sites



RCN Provider visits By Site



RCN Lab + Treatment Visits By Site



Looking forward

Opening of SCC in all regional



Presence APO for new visits



Expanding the age that can receive PT



Echocardiograms

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