

# State of CT Rare Disease Task Force

## Yale New Haven Children's Hospital Update

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Director, Pediatric Specialty Centers  
9/8/17

# YNHCH Vision Statement

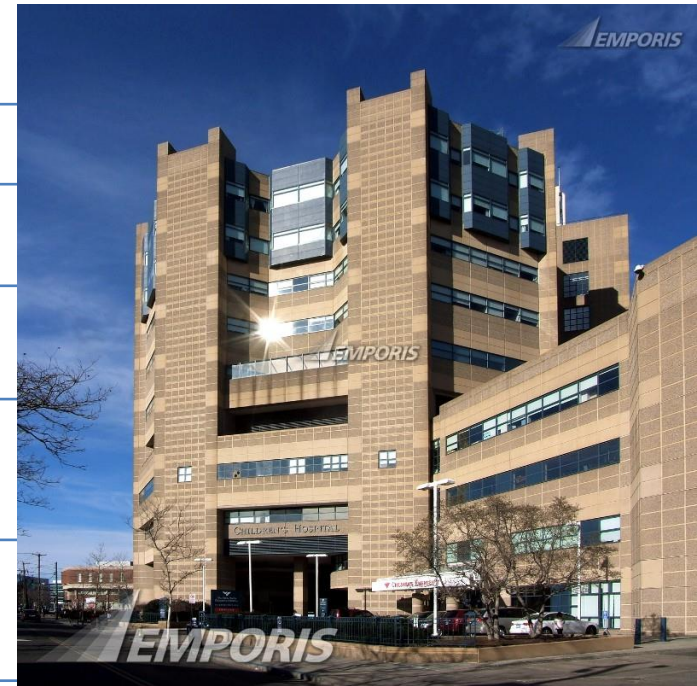
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*Yale New Haven Health System, aligned with Yale Medicine, will advance the Children's Hospital as a national and international leader in pediatric care, delivering innovative, personalized, and high-value patient centered care for children and their families.*



# Yale-New Haven Children's Hospital

<b>Opened</b>	1993	
<b>Total Beds</b>	222	
<b>Employees FTE</b>	1,200	
<b>Pediatric Medical Staff</b>	650 affiliated (137 specialists YSM)	
<b>Two Inpatient Campuses</b>	New Haven, Bridgeport 12,000 admissions	
<b>Specialized Inpatient Units</b>	<ul style="list-style-type: none"> <li>• Neonatal ICU (2)</li> <li>• Pediatric ICU</li> <li>• Hematology/Oncology</li> <li>• Neurosciences</li> <li>• Child Psychiatry</li> </ul>	<ul style="list-style-type: none"> <li>• Medicine/Cardiology</li> <li>• Bone Marrow Transplant</li> <li>• Solid Organ Transplant</li> <li>• Surgical Specialties</li> <li>• Medical Specialties</li> </ul>
<b>Specialty Center Network</b>	New Haven (3), Norwalk, Trumbull, Greenwich, Old Saybrook	
<b>Dedicated Facilities</b>	<ul style="list-style-type: none"> <li>• Emergency Department (37,000 visits)</li> <li>• Operating Room Suites (7)</li> <li>• Radiology Center, incl. MRI</li> </ul>	<ul style="list-style-type: none"> <li>• Cardiac Center, incl. Cath Lab</li> <li>• Infusion Center (3)</li> </ul>



# National Recognition

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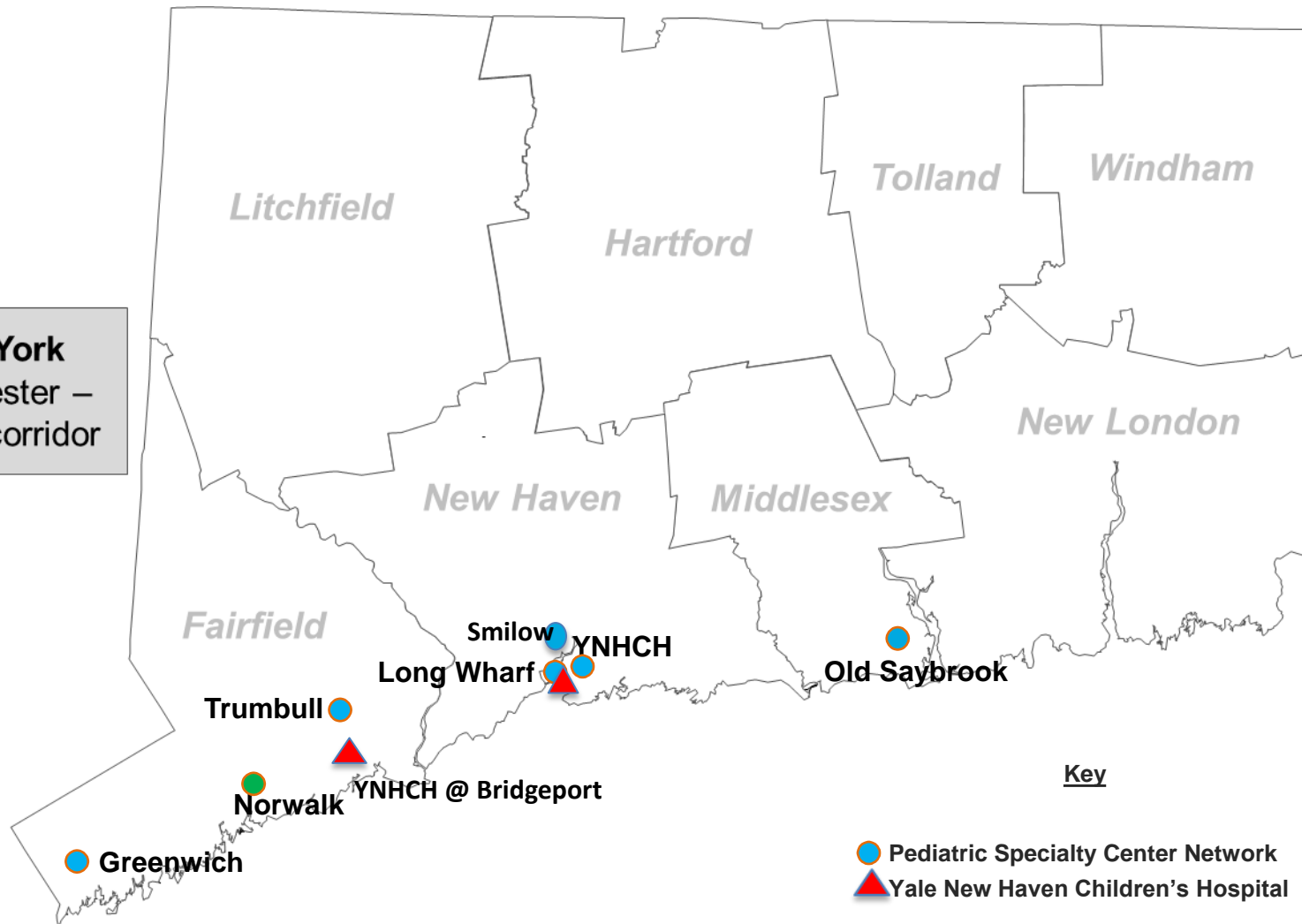
Ranked in 8 Pediatric Subspecialties in 2017  
best Children's Hospital rankings

- Cancer (#28)
- \*Cardiology & Heart Surgery (#42)
- Diabetes & Endocrinology (#4)
- Gastroenterology (#32)
- Neonatology (#29)
- Neurology & NeuroSurgery (#38)
- Pulmonology (#39)
- \*Urology (#45)

*\*Joint programs share with CCMC*



# YNHCH Pediatric Specialty Center Network



# Pediatric Specialty Center Network Sites

New Haven –  
Pediatric  
Specialty WP 2 &  
Smilow 7



New Haven –  
Long Wharf



Norwalk



Trumbull



Old Saybrook





CT REGIONS	E. Shoreline	New Haven			Fairfield County		
Specialties/Sites	Old Saybrook	YNHCH	Smilow	Long Wharf	Norwalk	Trumbull	Greenwich
Adolesc Comp							
Adoption							
Allergy/Immun							
Cardiology							
CT Surgery							
Craniofacial Surgery							
Develop/Behavioral							
Endo: General							
Endo: WT							
Endo: Diabetes Type I							
ENT							
GYN-Adolesc							
Genetics							
Gastroenterology							
Heme/Onc							
Infect. Disease							
Infusion Ctrs							
Nephrology							
Neurology							
Neurosurgery							
NICU Grad							
Ophthalmology							
Orthopedics							
Pediatric Surgery							
Respiratory							
Rheumatology							
Urology							

YNHCH

Pediatric Specialty Centers



Specialty at site



In development

Excludes all  
Multidisciplinary  
Programs

# YNHCH Pediatric Specialty Center: Multidisciplinary Specialty Sessions/Programs

Aerodigestive & Feeding Disorders	Muscular Dystrophy
Asthma	NICU Grad
Adult congenital heart	Weight Management
Celiac	Rare diseases/Genomics Program
Clotting Disorders	Sickle Cell
Concussion management	Sleep Disorders
Cystic Fibrosis	Spina BiFida
Diabetes Type I and II	Stone management
Downs Syndrome	Transitions to adult care
Epilepsy	Transgender
Hepatology/Transplant	Ventilator dependent
IBD and Crohns	Voiding Dysfunction



# Pediatric Specialty Ancillary Services/Sites

Service	YNHCH	LW	Norwalk	Trumbull	Old Saybrook
Cardiac Testing					
CT					
Fluoroscopy					
Interv. Radiology					
MRI					
Phlebotomy					
Pulm. Funct. Test					
Nuclear Med					
Rehab Services					
Sonography					
X-ray					

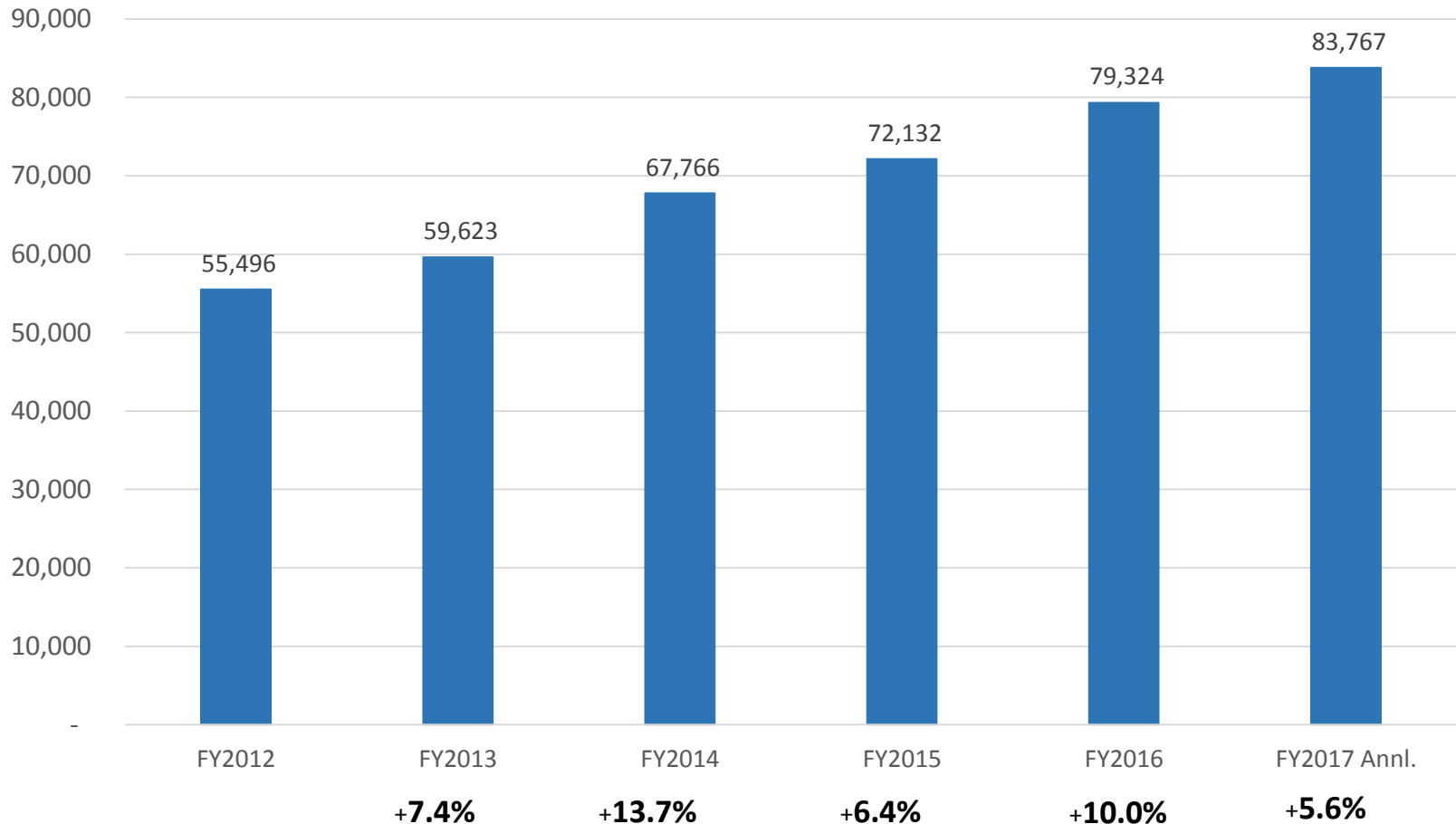
# Pediatric Specialty Center Network Care Model

- **Provide comprehensive array of specialty services for children with acute, chronic or terminal medical or surgical conditions**
- **Services are available in the communities in which children live**
- **Specially trained pediatric staff who is focus care on the developmental, behavioral and psycho-social needs of the patient and family.**
- **Care is coordinated through multidisciplinary teams:**

## **CARE TEAM:**

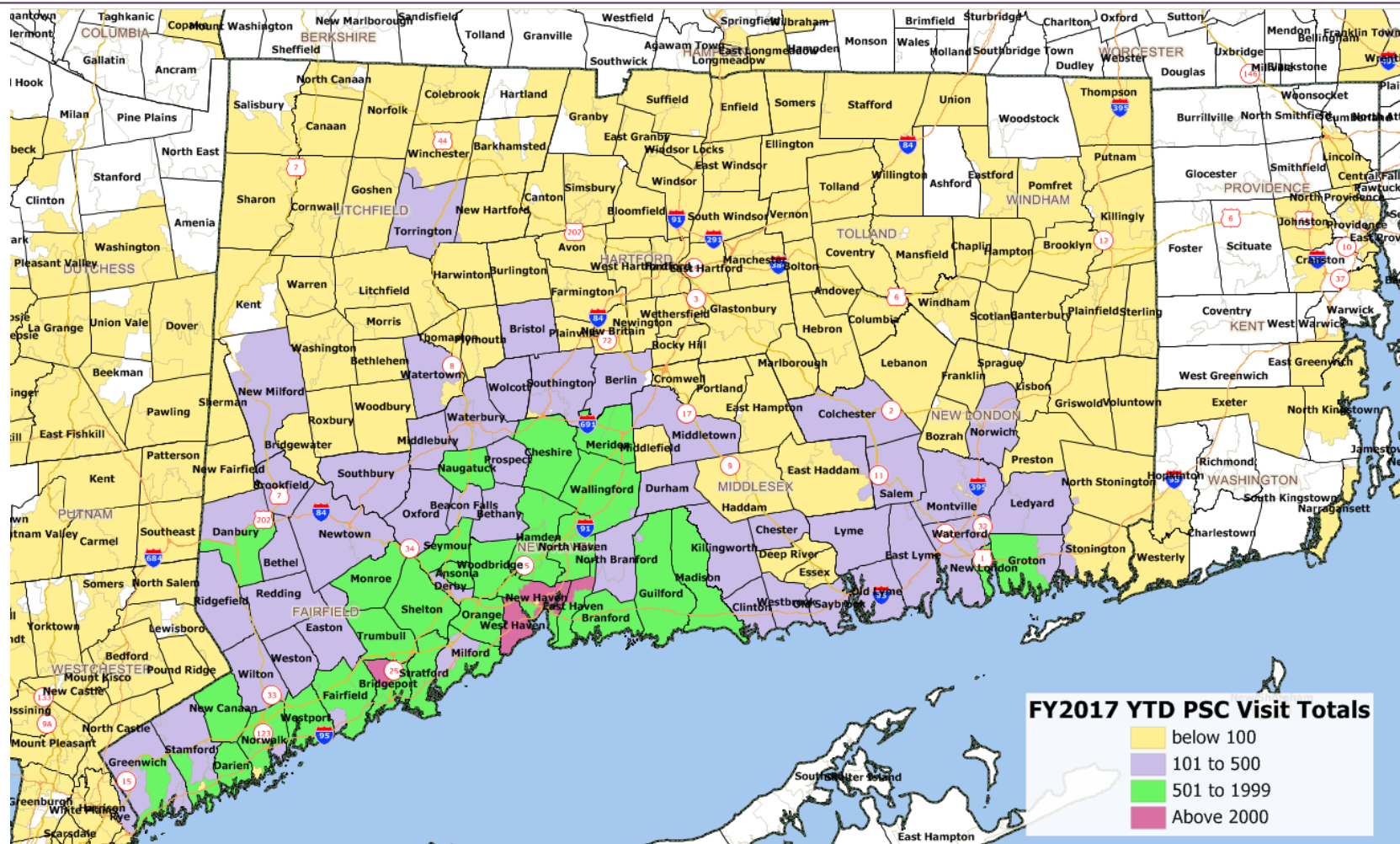
- Audiologists
- Board Certified Specialty Physicians
- Child Life Specialists
- Nutritionists
- Pharmacists
- Psychologists/Psychiatrists
- Registered Nurses
- Rehabilitation Specialists: Physical, Occupational and Speech Therapy
- Social Workers
- Technicians (Cast, Ophth, PFT)
- Unlicensed Assistive Personnel

# Pediatric Specialty Centers: Visit Volume

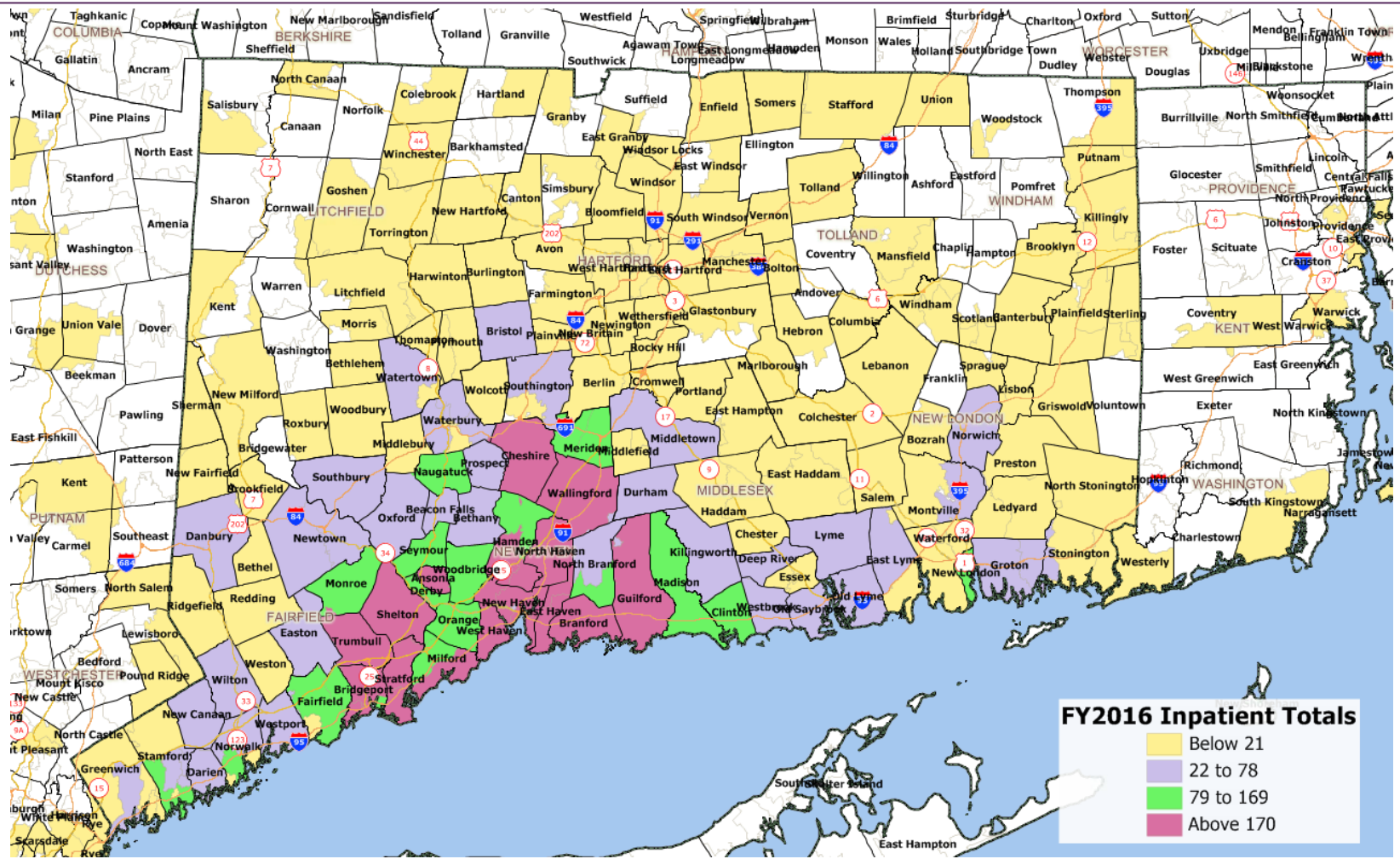


\*WP2, Long Wharf, Smilow, YBP, Norwalk, Trumbull, Greenwich, Old Saybrook

# PSC Patient Origin – FY 2017 YTD July



# YNHCH Inpatient Patient Origin – FY 2016



# **Pediatric Genomics Discovery Program (PGDP)**

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Mustafa Khokha, MD, Director

Saquib Lakhani, MD, Clinical Director

Michele Spencer-Manzon, MD, Genetics



# Pediatric Genomics Discovery Program

*Take part in a vital journey to help us discover new ways to detect and treat childhood illnesses.*





## PGDP: What is it?

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- When a child faces medical challenges, “*Rare Disease*” with no clear cause
- PGDP Team (clinicians and scientific researchers) collaborates with families to learn about the genetics basis for the child’s health problem
- Goal is to provide support (face to face or through other physicians) a diagnosis and parent’s understanding of what it means to the child’s health.
- Provide guidance and options for navigating the medical care options available
- Integrate genomic-based clinical care and research

# PGDP: Patient Referral Sources

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Internally: Yale New Haven Hospital

- Initial evaluation of pediatric patients with suspected rare genetics disorders who are in the hospital
- 1st inaugural Outpatient Specialty Clinic: May 5, 2017
- Prenatally from MFM/Obstetrics
- Pathology results

Externally:

- -Remote Consultations (research, through website)
- -In-person visits, phone, anywhere in the nation
- -Outreach to pediatrician practices
- -Marketing through brochures/website

# PGCDP: Research Opportunities

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- Evaluation of whole exome sequencing
  - Patients with negative clinical genetic testing
  - Develop functional testing assays appropriate for the particular disorder

Developmental biology/birth defects

Immunodysregulation

- Dedicated laboratories inside and outside of Yale
- Genomics Board: Collaborative meetings to combine all findings (clinical and research) into patient clinical recommendations.
- Volume growth
  - 2015: 16 patients (2 sequenced)
  - 2017: through April 45 patients (29 sequenced) anticipate 145

# YNHCH/Yale Medicine

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## **Pediatric Genomics Discovery Program**

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## **Yale New Haven Children's Hospital**

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