

# Arcus

Mid-Year Review 2022

# CONTENTS

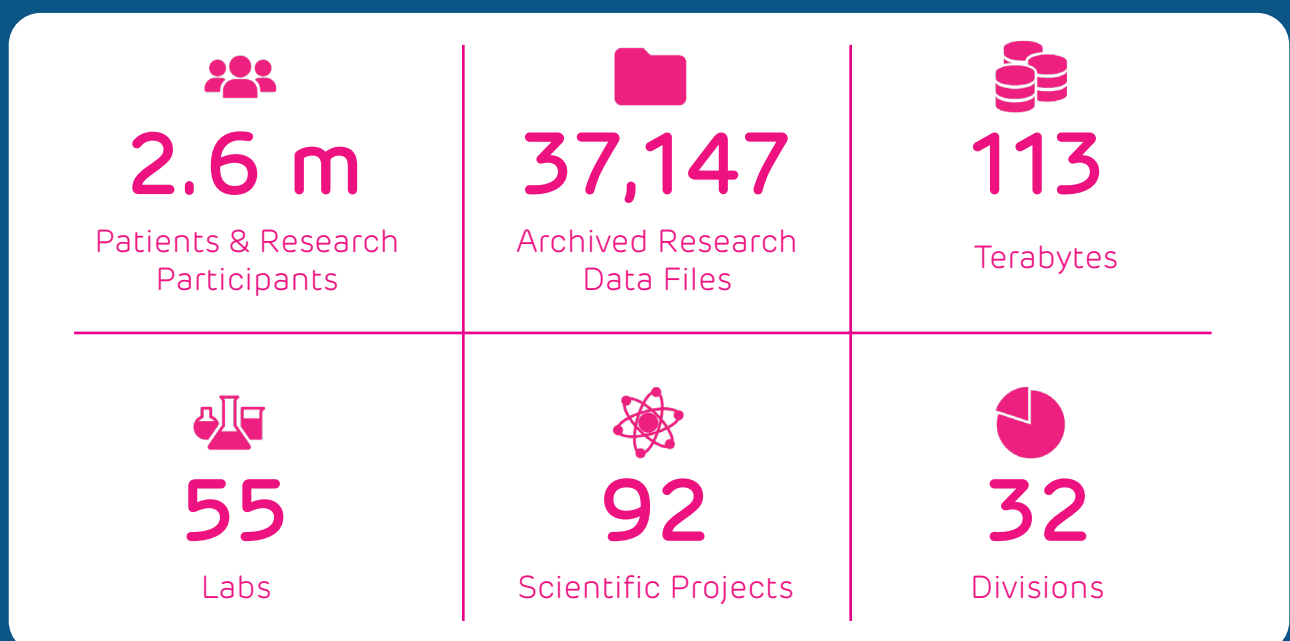
Performance Summary.....	1
Scientific Projects.....	2
Arcus Labs.....	3
Arcus Collaborations.....	4
Research Data Management.....	5
Arcus Education.....	7
Privacy.....	7
Scientific Projects Appendix.....	8

*“Bottom line, I am constantly looking to further develop my projects leveraging CHOP EHR data with Arcus because I know that Arcus will support me and allow me to fulfill my potential as a CHOP physician scientist.”*

*Ran Barzilay, MD  
Child & Adolescent Psychiatrist Research Scientist, Lifespan Brain Institute  
Department of Child and Adolescent Psychiatry and Behavioral Sciences*

## PERFORMANCE SUMMARY

Arcus impacts research across nearly half of CHOP’s Divisions.  
Research projects grew to 92, most are collaborations across multiple Divisions.

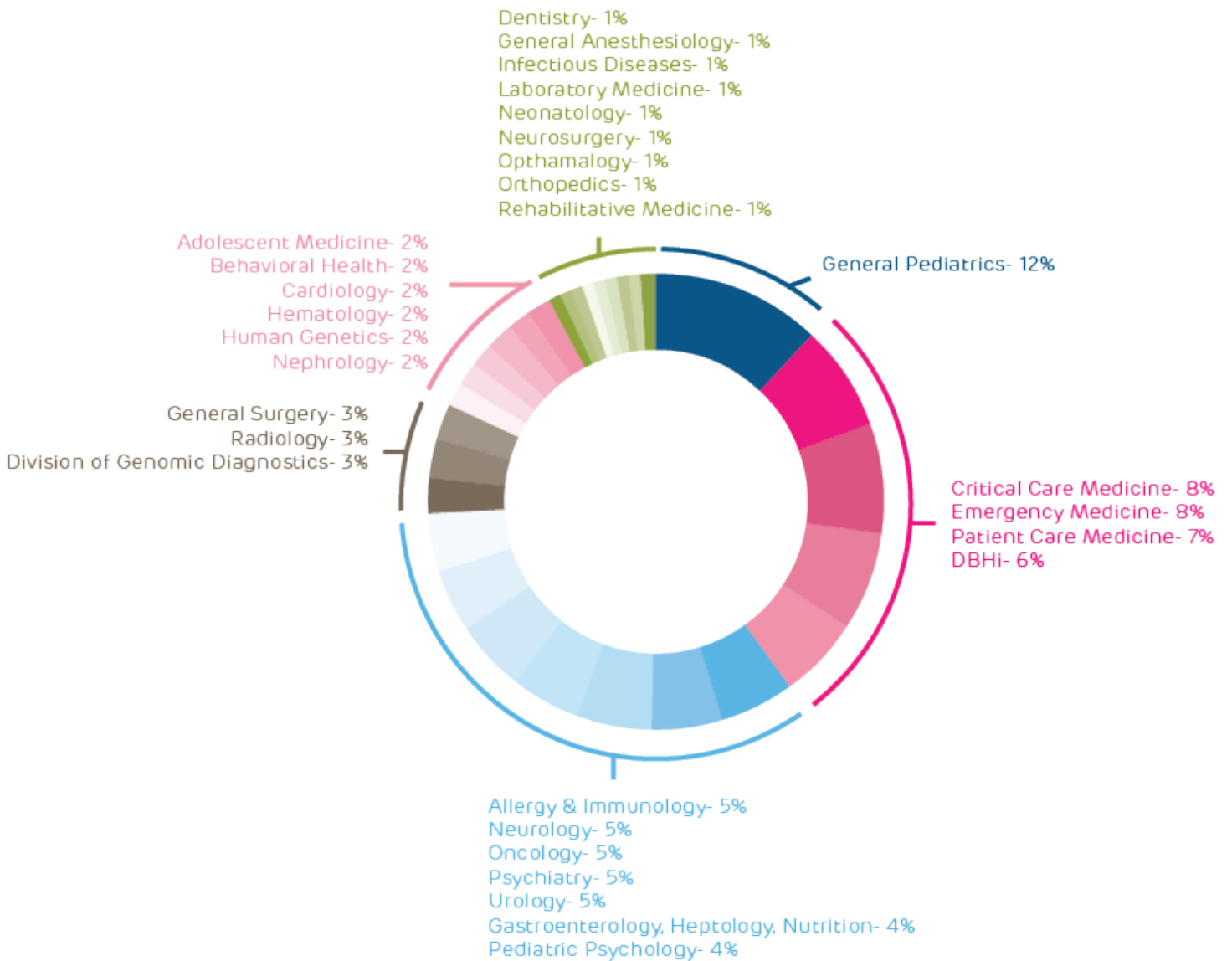


# SCIENTIFIC PROJECTS (By Division)

Scientific projects manage research efforts within Arcus by defining specific objectives, roles and responsibilities for both the research team and the Arcus team members and establishing a clear project management plan. To request an Arcus scientific project visit, <https://jira.arcus.chop.edu:8443/servicedesk/customer/portal/1>

*"The Arcus project owner directed every aspect of the development of the lab from set up through creation of the necessary shared drives. Using Arcus has removed a huge burden of processing this data. The project is ongoing and the computational lab can have other uses in the future, even connecting the data to medical records and collaborating with other groups doing this work."*

Jonathan Mitchell, PhD  
Research Assistant Professor of Pediatrics  
Division: Gastroenterology, Hepatology and Nutrition



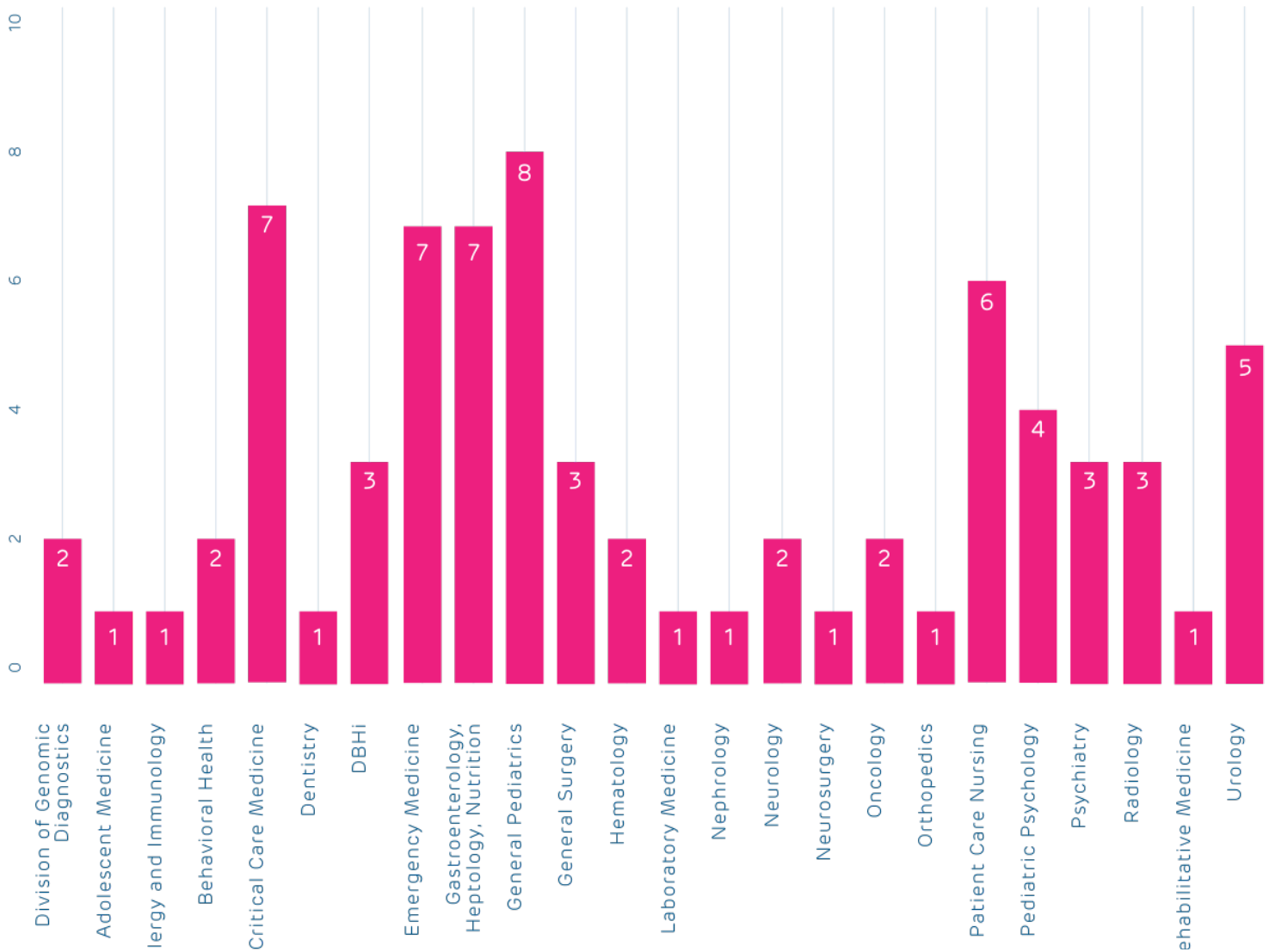
## ARCUS LABS (By Division)

Arcus Labs allow users to access data and includes tools to analyze data, all within their browsers. Training labs are available for new users to demo Arcus.

To request a training lab, visit <https://support.arcus.chop.edu/>.

*"Project management and planning with the Arcus team was the key to success... While the initial goal was to store and analyze data, our research team worked with Arcus project management to develop a complete image management process."*

*Gregory Tasian, MD, MSc, MSCE  
Associate Professor of Surgery and Epidemiology  
Division: Urology*



# COLLABORATIONS ACROSS DBHi

The Clinical Reporting Unit (CRU), Translational Informatics Group (TrIG), and the Data Science and Biostatistics Unit (DSBU) in the Department of Biomedical and Health Informatics work in collaboration with the Arcus team on many projects in the area of data management, depending on the specific needs and funding provided.

*The DSBU works with Arcus investigators to advise on methodology, structure/clean/manage data, create analytic datasets, analyze data and provide results in manuscript-ready formats.*

*Heather Griffis, PhD  
Director  
DBHi Data Science Biostatistics Unit*

## **DSBU Collaborations with Arcus**

Contact: Heather Griffis, PhD, Director, [griffish@chop.edu](mailto:griffish@chop.edu)

Title of Project: PSC-17P and PHQ-9 linkage study

PI: Claire Hatkevich

Title of Project: Alarm fatigue

PI: Halley Ruppel

Title of Project: Mental health/ED

PI: Joel Fein

Title of Project: Mental health and neuro outcomes

PI: Amy Jo Lisanti

Title of Project: Various projects

PI: Sarah Wood

## **Translational Informatics Group (TrIG) Collaborations with Arcus**

Contact: Alex Gonzalez, MS, MBA, Supervisor, [gonzalezak@chop.edu](mailto:gonzalezak@chop.edu)

Title of Project: Virtual Driving Tests in Primary Care

PI: Flaura Winston, MD, PhD

Title of Project: Videourodynamics Study

PI: Greg Tasian, MD, MSc, MCSE

Title of Project: Epilepsy Genetic Research Project (EGRP)

PI: Ingo Helbig, MD

Title of Project: Birth Defects Repository

PI: William Gaynor, MD

Title of Project Healthy Participants Study

PI: Sarah Henrickson, MD

# RESEARCH DATA MANAGEMENT

Working with Arcus helps researchers meet the requirements of [NIH's new data sharing policy](#) which will go into effect January 2023. Arcus librarians and archivists assist users with research data management (RDM) practices to organize, document, and preserve a research effort and its associated files, data, and context and it is at the core of the Arcus program.

*"Arcus data repository and data merging services are invaluable in helping our team analyze behavioral and medical data from nearly 20,000 adolescent patients seen in the CHOP Emergency Department since 2013. Specifically, they have facilitated the extraction of requested data from sources internal and external to CHOP, ensured that the construction and use of the database meets privacy and regulatory conditions, and problem solved with us as we consider how to identify new and modify existing data elements in the repository. Partnership with Arcus has allowed our study team to create an innovative and novel reservoir of medical and behavioral health detail pertinent to strengthening and promoting effective psychiatric and behavioral health care for adolescent patients treated in the CHOP Emergency Department and across the CHOP care network."*

*Joel Fein, MD, MPH  
Leah Brogan, PhD  
CHOP's Center for Violence Prevention*

## Data Consultations

Arcus Archivists consult with CHOP researchers to learn about the specific research and data sharing needs to ensure that data is accessible and reusable for specific individual projects, and when appropriate, for other CHOP researchers. The Arcus Library Science team works with researchers to make sure data is structured, organized, and clearly described.

Contact: Christiana Dobrzynski, MS, Digital Archivist, [dobrzynskc@chop.edu](mailto:dobrzynskc@chop.edu)

**Number of Consultations: 24**

**Number of individual researchers/ staff engaged via consults: 125**

**Number of resources providing expert data consulting: 22**

**Divisions/programs represented in consultations: 29**

Allergy and Immunology	General Pediatrics
Arcus/DBHi	General Surgery
Behavioral Health Services	Hematology
Birth Defects	Hematopathology and Immunology
Cardiac Critical Care Medicine	Human Genetics
Cardiology	Infectious Diseases
Cardiothoracic Anesthesiology	Lifespan Brain Institute
Center for Autism Research	Nursing Research
Center for Injury Research and Prevention	Oncology
Cerebral Monitoring/Frontier	Patient Care Services and Nursing
Data Science and Biostatistics Unit/DBHi	Proteomics
Emergency Medicine	Radiology
Emergency Psychiatry	REDCap
Endocrinology	Translational Research Informatics Group/DBHi
Gastroenterology, Hepathology and Nutrition	

## Data Contributions

Data Contribution	Total Files	Total Linked CHOP Patients and Research Participants
Division of Genomic Diagnostics (DGD)	15,496	5,240
Dynamic Microbiome	18,207	2,283
EGRP Epilepsy Genetics Research Project	2,308	601
PECARN Medical Record Registry	237	335,495
Reference Cohort	Total Queryable CHOP Patients and Research Participants in Arcus Data Repository (ADR)	
Healthy Participants	113,003	
Primary Care Birth	193,636	
Allergic Rhinitis	34,368	
Asthma	37,125	
Atopic Dermatitis	24,514	
Food Allergy (Allergic March)	7,846	
Sepsis	5,115	
Suspected Bacterial Infection	17,718	
Covid-19 Positive PCR Test	23,619	
Covid-19 Positive Serology Test	317	
Covid-19 POC Rapid Test	4,200	
Frontier FPIES Food Allergy	2,089	
Frontier EOE Food Allergy	4,721	
Frontier IgE Food Allergy	116,488	
Frontier Hyperinsulinism	4,681	

Data contributed to Arcus becomes part of the Arcus Archives, and powers discovery tools to support research efforts at CHOP. Contributing data to Arcus also means that Arcus will steward the data as part of its long-term preservation. [Contribute data to Arcus.](#)

Contact:  
Nicole Feldman, MSIS  
Digital Archivist  
feldmanna@chop.edu

# ARCUS EDUCATION

The Arcus Education team offers data education to help biomedical researchers leverage their use of Arcus tools and data. They provide one-to-one consulting, group workshops, office hours, asynchronous self-guided education, and user group meetings. You can find more information at the Arcus Education portal: <https://education.arcus.chop.edu>

Contact: Joy Payton, Supervisor, Data Education, [paytonk@chop.edu](mailto:paytonk@chop.edu)

*"Awesome mix of didactics and hands-on practice! Perfect way to dive into R."*

*"All of the content was presented in very easy to understand verbiage. The exercises were informative and very helpful in understanding the concepts. And the instructors are very knowledgeable and spoke clearly and at a great pace."*

*Anonymous Student Review from Arcus R Workshop*

## An Effort to Provide Data Science Education for All

As the recipient of an R25 training/education grant from NIH to provide data education to researchers at all levels, Arcus has begun the work of creating a large program of data science education to researchers both at CHOP and beyond. Currently in a pre-launch pilot phase, we're working with postdoc learners to hone our instrumentation and experimental design prior to conducting research and beginning the program in earnest. Whether CHOP researchers use Arcus labs or not, the eventual rollout of these materials will help with the acquisition of skills like programming in Python, tracking files using git, using the right statistical test, troubleshooting SQL, and creating compelling data visualizations.

We want to position researchers at the forefront of computational, reproducible research. To do that, we must go beyond the mere transmission of knowledge, but also package content in relevant, small, just-in-time modules. The grant centers around understanding what researchers need and providing focused, practical training that meets real researcher needs, on demand, knowing that not every researcher has the same interests or needs. Using a modular approach to learning, we plan to tap into the scientific and career motivations of investigators in order to "lift all boats" at CHOP and elsewhere.

## PRIVACY IN ARCUS

Privacy in Arcus follows the "Privacy by Design" proactive model anticipating privacy invasive events before they happen by building privacy measures into the design and architecture of our systems and processes. We consistently review and evaluate our data use standards and policies, in view of changing regulations and technologies through the use of Privacy Impact Assessments, or PIAs. In the last year, Arcus Privacy has conducted, concluded, and/or presented on the following PIAs:

- Omic Data
- Algorithms, AI, and Machine Learning in Arcus
- Mental Health Records in Research
- Health Information Exchange (HIEs) and Research
- Geolocation in Arcus
- Images in Arcus

Contact: Dianna Reuter, JD and CIPP/US, Research Privacy Manager, [reuterd@chop.edu](mailto:reuterd@chop.edu)



# SCIENTIFIC PROJECTS APPENDIX

Scientific Project	Description	PI
SCIT-5	Winston - Ohio Crash Predictors from Driving Simulation	Flaura Winston, MD, PhD
SCIT-6	Birth Defects Biorepository Data Cataloging, Access and Storage	William Gaynor, MD
SCIT-12	Sepsis: Leveraging Clinical & Biologic Data to Advance Clinical, Quality, and Scientific Efforts for Pediatric Severe Sepsis	Scott Weiss, MD, MSCE
SCIT-27	Division of Genomics and Diagnostics (DGD)	Nancy Spinner, PhD
SCIT-29	Microbiome - Dynamic	Robert Baldassano, MD; Kyle Bittinger, PhD
SCIT-33	Behavioral Health Phenotyping	Jami Young, PhD
SCIT-38	Local PECARN Registry	Joe Zorc, MD, MSCE ; Robert Grundmeier, MD
SCIT-41	Epilepsy Genetics Research Project (EGRP)	Ingo Helbig, MD
SCIT-43	CF-Computable Phenotype Glomerular disease	Christopher Forrest, MD, PhD
SCIT-49	Shape Analysis of Heart Valves	Matthew Jolley, MD
SCIT-51	Healthy Participants and Immunometabolic Dysregulation	Sarah Henrickson, MD, PhD
SCIT-71	Frontier: Molecular Basis of Food Allergy and Food Tolerance	Jonathan Spergel, MD, PhD
SCIT-81	CHOP Center for Rehabilitation Research registry	Laura Prosser, PT, PhD
SCIT-82	Adolescent Repository with EPIC and Medical Decision Logix (MDLogix)	Joel Fein, MD, MPH
SCIT-88	Allergic March Trajectories - OMOP Implementation	David Hill, MD, PhD
SCIT-89	Allergy March - Identify Novel Determinants that Associate with Specific Allergic Trajectories	David Hill, MD, PhD
SCIT-93	Image Classification of Liver Ultrasound Images to Identify Early Tumor Development in Patients with BWS	Jennifer Kalish, MD, PhD
SCIT-104	Pediatric Cardiac Arrests	Ryan Morgan, MD, MTR
SCIT-116	Develop Deep Learning Network to Identify 3D Center Line (curvature) of Spine	Saba Pasha, PhD
SCIT-117	VAN TZP: Piperacillin/tazobactam (TZP) and Vancomycin (VAN) Outcomes	Kevin Downes, MD
SCIT-120	RDoC Annotation Validation	John Herrington, PhD
SCIT-142	STI and HIV in Adolescents	Sarah Wood, MD, MSHP
SCIT-148	Sepsis Registry	Scott Weiss, MD, MSCE
SCIT-161	Creation of a Comprehensive Vascular Access (VAS) Database at CHOP	Aaron Chen, MD
SCIT-163	Sepsis: Linking Clinical and Genomic Data to Identify Research Questions	Scott Weiss, MD, MSCE; Fran Balamuth, MD, PhD

# APPENDIX (CONT'D)

SCIT-179	PKIDS Pediatric KIDney Stone - Phase 1 Internal Review at CHOP	"Gregory Tasian, MD, MSc, MSCE "
SCIT-184	Videourodynamics (VUDS) Machine Learning Analysis - Phase 1	"Gregory Tasian, MD, MSc, MSCE "
SCIT-185	Paradoxical Reaction to Benzodiazepines	Mallory Perry, PhD, RN CCCN
SCIT-194	Review of Port Complications	Myron Allukian, MD
SCIT-212	Neurobehavioral Morbidity Phenotype	Alicia Alcamo, MD
SCIT-216	Physical Activity	Jonathan Mitchell, PhD
SCIT-218	Clinical Data for CPTCA Biobank and DCC Submission	Kai Tan, PhD
SCIT-228	Weight Gain, Bone Geometry, and Functional Body Composition in Adolescents with Restrictive Eating Disorders	Rebecka Peebles, MD
SCIT-232	Explore MHC Variability/Haplotypes	Tristan Hayeck, PhD; Dimitrios Monos, PhD
SCIT-233	Bone Mineral Accretion in Young Children	Babette Zemel, PhD
SCIT-243	GIS Demonstration Project: Acute Lymphoblastic Leukemia (ALL) Maintenance Medication Adherence	Kelly Getz, PhD, MPH
SCIT-261	Philadelphia Beverage Tax Health Outcomes	Emily Gregory, MD, MHS
SCIT-321	Sepsis Vital Sign Exploratory Data Analysis in the PICU	Aaron Masino, PhD; Scott Weiss, MD, MSCE
SCIT-354	Behavioral Health Population Health Registry	Jami Young, PhD
SCIT-355	Provide Patient Similarity Scores for the ADR Cohort	Ingo Helbig, MD
SCIT-381	Machine Learning Method Development: Investigation of Feature Interaction in Biomedical Data	Jeffery Pennington, MSCS
SCIT-382	Identification of AML cell surface proteins for CAR T immunotherapies	Richard Aplenc, MD, PhD
SCIT-395	Shift Towards Telemedicine in CHOP Neurology During the Covid-19 Pandemic.	Ingo Helbig, MD
SCIT-404	Immune Deficiency (SCIT-404)	Sarah Henrickson, MD, PhD
SCIT-414	Proposal for CHOP EHR Analysis of Individuals At-risk for Psychosis Spectrum Disorders	Aaron Alexander-Bloch, MD, PhD; Raquel Gurr, MD, PhD
SCIT-442	Effect of Neurological Diagnosis on Anti-Epileptic Drug Utilization	Ingo Helbig, MD
SCIT-463	Circadian Rhythm	Jerome Taylor, MD; Raquel Gurr, MD, PhD
SCIT-478	ADHD Cross-Contextual Symptoms and Impairments	Jeremy Michel, MD, MHS

SCIT-480	Ureteropelvic Junction Obstruction	John Weaver, MD - Shukla Aseem MD
SCIT-486	Secondary Analysis of BHS Data + PNC cohort	"Ran Barzilay, MD "
SCIT-495	Utilizing Machine Learning to Predict Obstruction in Patients with Antenatal Hydronephrosis	"Gregory Tasian, MD, MSc, MSCE "
SCIT-506	Grant to Correlate Virtual Driving Test Data with CHOP Clinical Data\outcomes. (NJM Grant)	Flaura Winston, MD, PhD
SCIT-507	SCIT- 507 Urology Stone Machine Learning Project (P20)	"Gregory Tasian, MD, MSc, MSCE Antoine Selman-Ferman, MD Alex S. Felmeister, PhD "
SCIT-510	Long Term Follow up of CDH Patients Seen In Neonatology	"Elizabeth Froh, PhD, RN Joy Kerr Eloise Flood Darcy Brodecki"
SCIT-516	Emergency Department Triage and Resource Consumption	Warren Frankenberger PhD, RN; Joe Zorc MD
SCIT-517	Pediatric Sedation Phenotypes	Ruth Lebet, PhD, RN
SCIT-518	SDU Postpartum Care Encounters	"Elizabeth Froh, PhD, RN Joy Kerr Eloise Flood Darcy Brodecki"
SCIT-519	Patient Acuity Data Points	Mei Lin Chen-Lim, MSN, RN, CCRC
SCIT-525	EGRP EHR Phenotype Extraction	"Ingo Helbig, MD Michael Kaufman - KAUFMANMC@EMAIL.CHOP.EDU "
SCIT-558	Childhood Cancer Data Sharing to Support Target Discovery and Drug Development (Maris P30)	"John Maris, MD Deanne Taylor, PhD"
SCIT-559	Machine Learning on Ultrasounds to Predict Renal Outcomes in Patients with PUV	"Gregory Tasian, MD, MSc, MSCE Antoine Selman-Ferman, MD Alex S. Felmeister, PhD "
SCIT-570	Pediatric VTE	Leslie Raffini, MD
SCIT-583	Dissecting the Exposome's Role in Youth Suicidal Behavior in Youths Presenting to CHOP ED	"Ran Barzilay, MD Scott Haag Elina Visoki Jeffrey Miller Joel Fein"
SCIT-590	Epoch Race	"Barbara Chaiyachati, MD, PhD Atu Agawu"
SCIT-591	Maternal Mental Health Trajectory in Congenital Heart Disease	"Amy Jo Lisanti, PhD, RN Joanna Cole Abigail Demianczyk"
SCIT-605	Healthy MRI	Aaron Alexander-Bloch, MD, PhD; Raquel Gurr, MD, PhD
SCIT-607	SCIT-607 PRARIE Lab - Rib Fracture Detection on X-ray	Michael Francavilla, MD
SCIT-608	PRARIE lab - Club Foot Angles on X-ray	"Daniella Patton, ML, PhD Ray Sze - pediatric radiologist Michael Francavilla - pediatric radiologist"
SCIT-609	A Deep Learning Algorithm to Assess Ptois Surgery Outcomes	"Gil Binenbaum, MD, MSCE Karen Revere, MD - reverek@email.chop.edu Yvette Schein - Yvette.schein@penmedicine.upenn.edu"
SCIT-618	Pediatric Traumatic Brain Injury Database	Shih-Shan Lang Chen, MD
SCIT-632	Trustworthy AI for Pediatric ARDS	Raymond Sze, MD, MAMS
SCIT-641	Ontology Based Analysis of Clinical Phenotype Presentations in Pediatric Diseases	Kai Wang, PhD
SCIT-642	Emergency Department Utilization for Dental-Related Complaints	Kate Trieschman

SCIT-643	Machine Learning Prediction of Renal Complications after Equivocal MAG3 Renal Scans - Phases 1 & 2	"Gregory Tasian, MD, MSc, MSCE "
SCIT-652	PSC-17 and PHQ-9 Linkage Study	Claire Hatkevich, PhD; Jami Young, PhD.
SCIT-669	Use of Bone Marrow Derived Cells as a Preclinical Model for Gene Therapy Applications	Stefano Rivella, PhD
SCIT-678	Evaluation of Hematopoietic Cell Transplantation for Inborn Errors of Immunity	"Di Sun, MD, MPH - Kate Sullivan "
SCIT-684	HPO2Vector	"Jeffrey Miller, MSAS "
SCIT-694	Data to inform alarm management	"Halley Ruppel, PhD, RN Chris Bonafide, MD"
SCIT-705	eMERGE: Utilizing Polygenic Risk to Understand and Improve Outcomes: A Model For Overturning Health Disparities Through Minority-Enriched Genomics Healthcare	"Hakon Hakonarson, MD, PhD Naveen Muthu Jeritt Thayer John Connolly Patrick Sleiman Margaret Harr"
SCIT-707	AAV Gene Therapy Biorepository Project	"Lindsey George, MD "
SCIT-718	CKiD Actigraphy	Amy Kogon MD
SCIT-722	Assessing the Validity of an Online Clinical Tool to Evaluate Prevalence of Sexual Abuse and Assault in Adolescent Patients Presenting to a Pediatric Emergency Department	Joel Fein, MD, MPH; Barbara Chaiyachati, MD, PhD
SCIT-728	Physical Activity in Pediatric Pulmonary Hypertension (Avitabile K23)	Catherine Avitabile, MD
SCIT-747	Kerr_Neurogenic Bowel Dysfunction	"Elizabeth Froh, PhD, RN Joy Kerr Eloise Flood Darcy Brodecki"
SCIT-778	Teen Neighborhood Activity Patterns and Sleep (Teen NAPS) Study	"Stephanie Mayne, PhD "
SCIT-779	Investigating Correlates Between Asthma, Inflammation, and Suicidality in Children	"Ran Barzilay, MD "
SCIT-780	Lab Risk Prediction Tool	Gabe Zuckerberg
SCIT-796	Lab for ADS intern Daniel Schwartz	"Scott Haag, PhD "
SCIT-779	Allergy and Suicidality	Laura Prosser, PT, PhD