



JOHNS HOPKINS

INSTITUTE *for* CLINICAL &
TRANSLATIONAL RESEARCH

Integrating Special Populations: A New ICTR Core

Todd Brown MD, PhD

Integrating Special Populations



GOAL: Expand the range of special populations participating in clinical and translational research at Johns Hopkins

- Promote broad inclusion in research studies (age, sex/gender, race, limited English proficiency)
- Establish a robust consultative network for accessing special populations for inclusion in clinical and translational research
- Foster collaborations to access large cohorts of special populations
- Provide expertise for research methods involving special populations

ISP: Expanding the range of special populations participating in clinical and translational research



- Population Liaison Service: a robust consultative network to access special populations for inclusion in clinical and translational research
- Five Special Populations Identified:
 - Geriatrics
 - Pediatrics
 - Rare Diseases/Genetics (KKI)
 - Under-represented Minorities
 - Acute Care/Trauma (Univ of Maryland)
- Three routes of access depending on needs
 - Population Liaisons: content experts
 - Recruitment Innovation Network
 - Informatics Population Liaison (use the EMR to identify a subset of a special population)

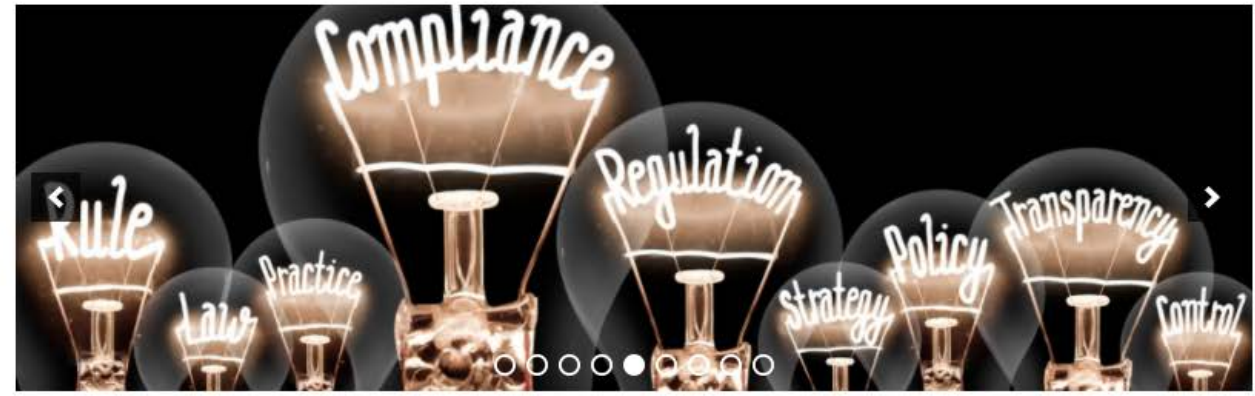


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PROGRAMS & RESOURCES

BROWSE: [Home](#) / [Programs & Resources](#)



We offer a variety of programs and resources to members of the Johns Hopkins research community who are currently preparing or executing clinical research. From clinical infrastructure, nursing and laboratory services, we are prepared to address the most pressing needs of clinical investigators.

New Program! Integrating Special Populations into Research Program (ISP)

Capital Region Research (CAPRES)



CONTACT

TODD T. BROWN

Professor of Medicine and Epidemiology

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INTEGRATING SPECIAL POPULATIONS INTO RESEARCH PROGRAM (ISP)

BROWSE: [Home](#) / [Programs & Resources](#) / [Integrating Special Populations into Research Program \(ISP\)](#)

The Integrating Special Populations into Research Program (ISP) facilitates access to the varied populations at Johns Hopkins and affiliated institutions.

Attend our presentation at the Third Thursdays with the ICTR Lecture

August 19, 2021 at 1:00 pm

[Register](#)

Are you looking to expand your research study to increase diversity in age and race/ethnicity? Are you interested in finding potential participants with Rare Diseases? Do you want to learn research methodologies specific to Special Populations? The ICTR can help.

Our Methods

We provide consultations with our Population Liaisons who are experts with knowledge of 4 broad populations that are critical to the mission of expanding research participation.

- **Geriatrics**
- **Pediatrics**
- **Genetics/Rare Diseases**
- **Underserved Minorities.**

To initiate a consultation with the ISP team, please complete an intake form that will tell us a bit about your project and the type(s) of assistance we can offer you. You will receive a response in 3-5 business days.

Submit an Application for Assistance

<https://redcap.link/JHUISP>.

You can also request assistance from our research navigators via email at ICTR_Navigators@jhmi.edu.



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ISP Intake Form

Resize font:
⊕ | ⊞

Thank you for your interest in working with the ISP. Please complete the form below and we will respond within 3-5 business days.

Thank you,

Todd Brown, MD, PHD
and
The ICTR Navigators

General Contact Information

Are you submitting this request on behalf of a principal investigator?

- ☐ Yes
☐ No

reset

Does the Principal Investigator have a JHED ID?

- ☐ Yes
☐ No

reset

Proposed Study Background

Which Special Patient Population are you interested in?

- ☐ Pediatrics
☐ Geriatrics
☐ Underserved Minorities
☐ Genetics/Rare Disease

Which of the following are you interested in requesting from the ISP?

- ☐ 1. Speaking with a faculty expert about recruiting in this population or using population specific methodologies
☐ 2. Getting advice on how to recruit this population from the Recruitment Innovation Unit
☐ 3. Getting help from Informatics about how to use the electronic health record to get summary statistics about a population
☐ 4. Identifying a collaborator who works with a specific population
☐ 5. Other, please specify below

Please let us know of any other efforts you have made prior to reaching out to the ISP core for assistance

Expand

What is your protocol's title?



CONTACT

LINDA POST

Research Navigator

Submit an ICTR Connection Request |

ICTR_Navigators@jhmi.edu

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ASK THE RESEARCH NAVIGATOR

BROWSE: [Home](#) / [Request A Service](#) / [Ask the Research Navigator](#)

The ICTR Navigator is here to help direct investigators to the ICTR services they need and advise them on “next steps” in the clinical and translational research enterprise at Johns Hopkins. If you’re not sure where to start, submit an ICTR Connection Request.



Services Provided

Select examples of frequently requested assistance include:

- Referral to appropriate ICTR (and JHU) resources, services, and programs
- Direction to applicable Institutional policy and guidance
- Direction to help and navigation resources for users of ICTR and institutional electronic systems (e.g. Qualtrics, CRMS, eIRB, CRUOnline)
- Direction to Human Subjects Training information and training requirements
- Providing general information about internal and external funding opportunities
- Providing educational sessions for divisions, departments and individual study teams about the resources available within the ICTR and across JHU to support specific research programs and projects

Ask a Navigator Handout



CONTACT

CASSIE LEWIS-LAND

Research Program Manager

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RECRUITMENT INNOVATION UNIT CONSULTATION

BROWSE: [Home](#) / Recruitment Innovation Unit Consultation

We provide consultation and coaching on the recruitment and retention of diverse research participants using evidence based and field tested methods.

Our team offers advice and guidance to help investigators and research staff identify and address recruitment barriers. Our consultants have experience with technology and community-engaged recruitment strategies.

We provide recruitment support in the following areas:

- Needs assessment
- Study design assessment
- Pre-screening/cohort discovery
- Outreach to stakeholder partners
- Customized recruitment and retention plans
- Troubleshooting recruitment challenges
- Gathering feedback from the ICTR Community Research Advisory Council (C-RAC)
- Creating a recruitment timeline
- Developing strategies to increase enrollment and retention
- Assessing feasibility of recruitment methods given a target population

Submit a Connection Request

Browse Topics: [Patient Recruitment](#)



CONTACT

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IT Manager
| mmitra2@jhu.edu

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CORE FOR CLINICAL RESEARCH DATA ACQUISITION (CCDA)

BROWSE: [Home](#) / [Programs & Resources](#) / [ICTR Informatics Core \(i2c\)](#) / [Core for Clinical Research Data Acquisition \(CCDA\)](#)

The Core for Clinical Research Data Acquisition (CCDA) assists researchers with accessing clinical data for research purposes. The CCDA is staffed with experienced data analysts who will assist you with access to data while also helping you comply with Data Trust privacy and security regulations.

Contact Us

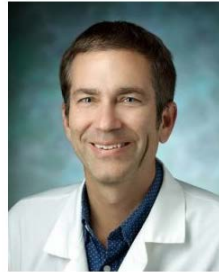
- + Who is the CCDA?
- + What Services Are Provided?
- + Why is There a Charge?
- + Who Are Our Customers?
- + What Data Sources Are Available?
- + What Data Do We Provide?
- + What Data Is Available in Epic?
- + How Do I Get Started?
- + What Information Is Considered When Structuring a Request?
- + How Can the CCDA Assist Me in Ensuring Compliance with IRB and Data Trust Best Practices?
- + How Long Does a Project Usually Take?

Annual Reports



Geriatrics Population Liaison:

Jeremy Walston, MD, Johns Hopkins University



Dr. Walston is the Raymond and Anna Lublin Professor of Geriatric Medicine at Johns Hopkins University where he is a clinical geriatrician and translational researcher in the area of the biology of frailty. He is the Principal Investigator of the Older American Independence Center which provides an outstanding resource for investigators interested in etiologic frailty research, and research to develop and test prevention and intervention strategies in human subjects. Walston will help investigators interested in specific geriatric populations to find collaborators/cohorts, as well as provide recommendations for research methodologies in this population.

Pediatrics Populations Liaisons:

Corrine Keet, MD, MS, PhD, Johns Hopkins University



Dr. Keet is an associate professor of pediatrics in the Division of Allergy Immunology and conducts clinical, epidemiologic and translational research aimed at better understanding and treating pediatric allergic diseases, particularly food allergies. Dr. Keet's NIH funded research centers on the epidemiology and treatment of food allergy and other pediatric allergic diseases. She focuses on characterizing the "food allergy epidemic", identifying environmental risk factors for food allergy and other allergic diseases, and on prevention and treatment of food allergy. She also serves as the director of the Pediatric Clinical Research Unit. Keet will help investigators find specific pediatric populations at Johns Hopkins and consult on pediatric research methodologies.

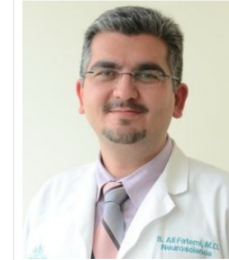
Neil Goldenberg, MD, PhD, Johns Hopkins All Children's Hospital (St. Petersburg, Florida)



Dr. Goldenberg is Professor of Pediatrics and Medicine and a pediatric hematologist/oncologist at Johns Hopkins All Children's Hospital in St. Petersburg, Florida. He is also the associate dean for research and the director of the Johns Hopkins All Children's Hospital Institute for Clinical and Translational Research. He is an international leader in the field of venous thromboembolism in children and young adults and recently completed patient enrollment for his clinical trial that studied the duration of anti-clotting medication therapy for venous thromboembolism in patients under 21 years old. Given his position as the associate dean for research, Dr. Goldenberg is a resource for investigators outside of All Children's Hospital to access multiple pediatric populations.

Rare Diseases Populations Liaison:

Ali Fatemi, MD, Kennedy Krieger Institute; Johns Hopkins University



Dr. Fatemi is an associate professor of neurology and pediatrics at Johns Hopkins University and a pediatric neurologist at the Kennedy Krieger Institute with expertise in leukodystrophies and other rare neurogenetic disorders affecting neurodevelopment. He is a founding member of the Board of Directors of a rare disease network ALDConnect, an all-inclusive multinational consortium for patients with X-linked adrenoleukodystrophy (ALD), whose goal is to harmonize multi-center data collection and conduct multi-center clinical trials. He has worked closely with advocacy groups and foundations to gather natural history data on these individual disorders and in developing therapeutic strategies. With this objective, he serves as a member of scientific advisory boards to several patient advocacy groups, industry partners and the Patient-Centered Outcomes Research Institute (PCORI) rare disease Task Force. As the co-director of the Intellectual and Developmental Disabilities Research Center at Kennedy Krieger, he is also involved in the coordination/supervision of many research projects through our various research cores. He is a superb resource for investigators interested accessing populations with rare genetic diseases.

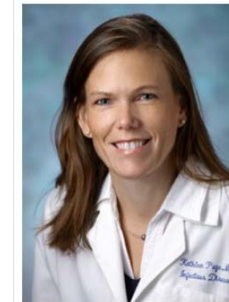
Underserved Minority Populations Liaisons:

Lisa Cooper, MD, MPH, Johns Hopkins University



Dr. Cooper is a professor of Medicine, Epidemiology, and Health, Policy, and Management, holds the James Fries Chair in Medicine, and is a Johns Hopkins University Bloomberg Distinguished Professor. Dr. Cooper is a general internist, social epidemiologist, and health services researcher. She is one of the first scientists to document disparities in the equality of relationships between physicians and patients from socially at-risk groups and her research program examines the effectiveness of patient-centered strategies for improving health outcomes and overcoming racial and ethnic disparities in healthcare. She will help investigators access minority populations in Baltimore.

Kathleen Page, MD, Johns Hopkins University



Dr. Page is an associate professor of medicine in the Division of Infectious Diseases. Page's research focuses on addressing disparities in health care, particularly among Latinx immigrants. She is the co-founder of [Centro SOL](#), a Johns Hopkins Center of Excellence in Latino Health with a mission to promote equity in health and opportunities for Latinxs. Centro SOL is involved in a variety of activities, such as improving services for patients with Limited English Proficiency, developing culturally-sensitive mental health resources for the community, and engaging Latino mothers to be pro-active members of our Latino family advisory board. Centro SOL also provides consulting services for researchers wishing to engage Latinx populations by helping with participant recruitment, material review and translation, bilingual staff support, and culturally-appropriate study design.



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JOHNS HOPKINS UNIVERSITY

✚ OLDER AMERICANS ✚ INDEPENDENCE CENTER

Funded by the National Institute on Aging, P30-AG021334

Welcome. Please use the following links to:

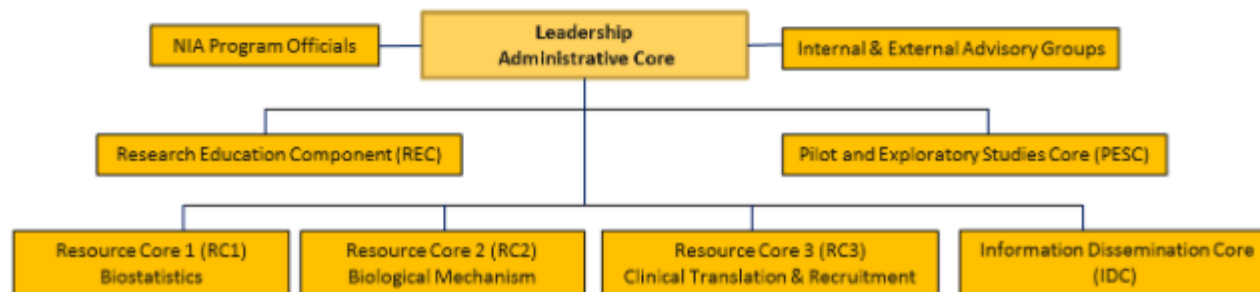
- Visit our new online resource: FrailtyScience.org
- Access the Online Frailty Assessment Calculator
- Explore OAIC Funding Opportunities
- Learn about ongoing OAIC Frailty Research
- Participate in the Pepper Scholars Program
- Review OAIC-supported Publications and Grant Awards

Center Overview

Co-Principal Investigators: Jeremy Walston, MD and Karen Bandeen-Roche, PhD

Frailty is recognized as an age-related condition in which older adults lose the capacity to cope with stressors and become vulnerable to functional decline, loss of independence, and mortality. Since its original funding in 2003, the novel approaches of the **Johns Hopkins University (JHU) Claude D. Pepper Older Americans Independence Center (OAIC)** have helped to demonstrate that frailty is a syndrome caused by multiple biological mechanisms that are expressed through characteristics of decreased resiliency and reserve in older adults. Frailty research provides a highly productive framework for clinical, population-based and biological discovery and for the development of junior investigators for academic careers in frailty and aging research.

The mission of the JHU OAIC is to provide a hypothesis-driven, frailty-focused, highly interdisciplinary center where supported investigators receive the expertise, resources, and training necessary to make fundamental discoveries related to the origins and causes of frailty and then move these discoveries towards frailty-focused interventions.



The JHU OAIC has **seven cores** that work synergistically to accomplish these goals. Please [click here](#) to learn more about the key functions and projects of each core.



FRAILITY SCIENCE

Promoting Resilience and
Healthy Aging



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COVID-19: Information and Resources – a note from FrailtyScience.org



Our mission is to provide state-of-the-art information on frailty-related science and how it might impact health and wellness for older adults. Our goal is to improve the understanding of how frailty develops, how to best assess it, and how to best treat and prevent frailty-related decline.



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About Us

The Johns Hopkins Center for Health Equity (formerly known as the Center to Eliminate Cardiovascular Health Disparities). The Center is led and founded by Dr. Lisa Cooper, James F. Fries Professor of Medicine and Johns Hopkins University Bloomberg Distinguished Professor.



WHO ARE WE?

We are highly committed change agents. We are working to make healthcare institutions more equitable, communities more engaged, and health policies and practices more effective so as to eliminate disparities in health and healthcare in Baltimore, the United States, and the world. Our team includes 40 Center faculty and 20 staff, trainees, community advisory board, advisory board, and partners. Our experience spans upwards of 30 years of innovative research and practice.

WHAT DO WE STRIVE FOR AND HOW WILL WE ACHIEVE IT?

We are driven to advance effective health system and community practices and policies that will achieve health equity in the U.S. and around the world; we achieve this through leadership, research, community engagement, education, and policy translation. We promote equity in health and healthcare for socially at-risk populations through advancing scientific knowledge, educating and training scholars, engaging and partnering with communities, raising public awareness of health inequities, and advocating for changes in clinical practice and policy.

Health inequity is a complex problem that requires careful investigation from multiple perspectives. To address this multi-faceted challenge, our approach involves the following key strategies:

1. RESEARCH AND TRANSLATION
2. EDUCATION AND TRAINING
3. COMMUNITY ENGAGEMENT
4. PUBLIC POLICY
5. LOCAL GLOBAL LEARNING

Learn more about the Center history, our team, and our strategic approach to addressing health inequities.



Learning Resources

Understanding the concept of health inequities and how best to contribute to advancing health equity can be complicated. Our team is learning more about these complexities everyday and we're eager to share this knowledge widely.



Below you'll find access to our latest resources, whether you're a researcher, student, journalist, private citizen, health practitioner, community leader, policy maker, or funder.

TRAINING COURSES

We have degree courses designed for students, researchers, and other health professionals. We also have massive open online courses (MOOCs) if you're not positioned to complete a degree course.

- > [Degree Courses](#)
- > [Online Learning MOOC Courses \(non-degree\)](#)

PUBLICATIONS

We share latest news, knowledge, and lessons learned from our work in action. These include a collection of peer-reviewed academic journal articles, opinion pieces, and commentaries, along with free subscription to receive our monthly or quarterly news updates and stories, annual reports and books.

- > [Academic Publications by CHE team](#)
- > [CHE Research News and Stories Publications](#)

LEARNING LIBRARY

Multimedia learning resources available in our Online Learning Library include: Primer Materials (Factsheets, Brochures, References), Frequently Asked Questions, Video and Image galleries

- > [Online Learning Library](#)



BEST PRACTICES IN HEALTH EQUITY RESEARCH, EDUCATION + COMMUNITY INVOLVEMENT

Online Learning Courses



ONLINE LEARNING COURSES

NEW WAYS TO GET A WORLD CLASS EDUCATION

Eager to become a better health practitioner? Looking to accelerate your career? Want to learn from leading health experts at the top-ranked university for public health in the United States?

Now you have access to teaching by some of the best health researchers and practitioners in the USA. The online courses offered by the interdisciplinary Center for Health Equity incorporate leading experts from the **Johns Hopkins Bloomberg School of Public Health** (ranked No.1 in 2019), **School of Nursing** (ranked No.1 in 2019) and **School of Medicine** (ranked No.2 in 2019).

** Rankings from U.S. News & World Report which includes more than 60 public health schools and over 100 programs accredited by the Council on Education for Public Health.*

MASSIVE OPEN ONLINE COURSES (on Coursera)

Foundations of Health Equity Research



MISSION

[Learn More](#)

At Centro SOL we promote equity in health and opportunity for Latinos

by advancing clinical care, research, education, and advocacy at Johns Hopkins and beyond in active partnership with our Latino neighbors.

Our Impact

Centro SOL was founded in 2013 by passionate physicians who saw a need in the Baltimore community. There wasn't a lot of outreach for the growing Latino population in Baltimore City so they set out to do the work themselves.

Structure & Outcomes



[Home](#) > [What we do](#) > [Research and Policy](#)

Centro SOL conducts research to contribute to the evidence base for improving Latino health, provides services for researchers interested in conducting research with Latino populations, and advocates for positive policy changes to improve health and opportunities for Latinos.

Research



Policy



Publications



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Research

Research is a central part of Centro SOL's activities. Centro SOL faculty are members of the Johns Hopkins University School of Medicine and bring decades of experience to their research. Research at Centro SOL is driven by the unique health issues faced by the Latinx population in Baltimore and beyond.



Research Services

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In addition to conducting independent research, Centro SOL began offering research consultation services in 2015 in response to a large number of requests from researchers interested in researching issues affecting Latinx health in Baltimore City.



Geriatrics

Jay Magaziner



Dr. Magaziner, the chair of the Department of Epidemiology and Public Health, leads the campus- wide Center for Research on Aging and is the principal investigator of our Pepper Center. He is able to bring multidisciplinary research teams of basic, clinical and population scientists together to address important and complex problems related to aging, health and disability. He will help investigators leverage extensive resources from the aging programs at UMB.

Barbara Resnick



Dr. Resnick is a Professor, Chair in Gerontology and Co-Chair of the Biology and Behavior Across the Lifespan Center for Research at the UMB School of Nursing. Over the past 20 years, Dr. Resnick has developed multiple combined exercise and motivational interventions for older adults which have been used in a variety of settings including the Exercise Plus Program for hip fracture patients and the Restorative Care Intervention, now referred to as Function Focused Care. Dr. Resnick helps investigators access to geriatric populations through her relationships with long term care facilities and community based settings, locally, nationally, and internationally.

Pediatrics

Maureen Black



Dr. Black is Professor and Division Chief of Growth and Nutrition in the in the Department of Pediatrics, UMB School of Medicine. She directs an interdisciplinary Growth and Nutrition clinic for children with growth and/or feeding problems, and has successfully implemented family-based strategies to promote healthy growth and development among young children. She specializes in the prevention of health disparities associated with threats to children's early development, including poverty, nutritional deficiencies (food insecurity) and prenatal drug exposure. Dr. Black will help investigators access pediatric populations.

Under-Represented Minorities

Shyam Sundaran Kottlil



Dr. Kottlil is a Professor of Medicine, Director of the Division of Infectious Diseases and the Division of Clinical Care and Research at the Institute of Human Virology (IHV) at UMB. His research interests have focused on directing large clinical trials in underrepresented minorities investigating novel treatment approaches to treating hepatitis B and C virus (HCV) in mono-infected patients and patients co-infected with HIV. His ongoing efforts are focused on implementation of strategies to expand clinical therapeutics to achieve functional cure for HIV and HBV infections, and establishing correlates for sustained virologic responses to HCV. Dr. Kottlil will help investigators access underrepresented minority populations.

Rare Diseases/Genetics

Alan Shuldiner



Dr. Shuldiner is a Professor of Medicine and Director of the Program for Personalized and Genomic Medicine at UMB. His major research interests lie in the molecular biology and genetics common complex diseases and traits including type 2 diabetes, obesity, and cardiovascular disease that contribute significantly to mortality, morbidity, and functional loss. He also works on the pharmaco- and nutri-genomics of these disorders and the translation and implementation of evidence-based genomic medicine into clinical practice. In 1995, Dr. Shuldiner founded the Amish Research Clinic. Since that time, he and his multidisciplinary research team have enrolled more than 6,500 subjects from this unique founder population into more than a dozen NIH-funded studies of complex diseases and traits. As Director of the University of Maryland Amish Research Clinic,

Dr. Shuldiner will provide JUH-UMB CTSA investigators access to resources of the Amish Research Clinic to enable their research. He will also share his expertise with CTSA investigators who wish to incorporate genetics into their clinical research.

Acute Care/Trauma

Thomas Scalea



Dr Scalea is The Honorable Francis X. Kelly Distinguished Professor of Trauma Surgery at University of Maryland School of Medicine, Physician-in-Chief, R Adams Cowley Shock Trauma Center and Director, Program in Trauma. The center is the busiest trauma center in the State of Maryland and is one of the busiest trauma centers in the country with over 6,000 primary trauma admissions per year. He will assist ICTR investigators who wish to access acute care/traumatic injury patients in their clinical and translational research.



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Questions?