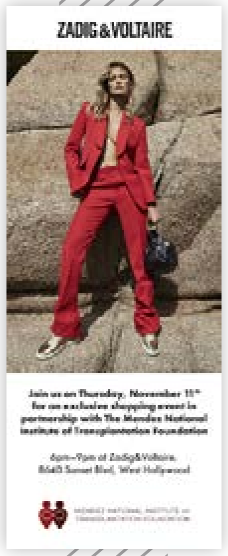
evolving with change

2021

MENDEZ NATIONAL INSTITUTE OF
TRANSPLANTATION FOUNDATION

CONTENTS

A special thank you to Zadig & Voltaire
for partnering with MNITF and hosting a shopping event.



EVOLVING WITH CHANGE

A LETTER FROM THE EXECUTIVE DIRECTOR

Dear friends,

Welcome to the 2021 edition of the MNITF magazine. Many of us hoped 2021 would allow a return to some form of pre-pandemic life as COVID-19 vaccines became available to the general public. While there has been progress, the onset of the Delta variant has meant a continuation of the global pandemic, with those in vulnerable populations most heavily affected. For MNITF, 2021 has been about embracing the current healthcare landscape and innovating new ways to help the transplant community move forward despite many challenges. That's why the theme we've selected for this year's magazine is **Evolving with Change**.

It's widely known that dealing with COVID-19 has placed an extraordinary strain on the healthcare system. Still, most people aren't aware that medical research has been negatively impacted during the pandemic. Due to strict policies, most laboratory research stopped in 2020, and when it was resumed, it was at a 25% capacity. During this time, students did not have the opportunity to receive in-laboratory training, and doctors had to stop or slow down patient enrollment. MNITF has been determined to meet the need for research during this crisis and recently funded three promising grants. Two of the grants are from early-stage researchers and address increasing the life span of liver and lung transplants. The third grant aims to improve the lives of immunocompromised individuals by testing whether a COVID booster shot consisting of twice the amount of immune stimulus produces better immune responses in transplant recipients. You can read about these groundbreaking studies and their potential to improve the lives of transplant recipients in this issue.

Despite the pandemic, MNITF remains at the forefront of creating targeted education that directly addresses the needs of vulnerable populations. *Linked by Love*, our next digital edutainment series, will address the significant racial and healthcare disparities experienced by African Americans, who are most disproportionately affected by kidney disease. With scripts now written for the six-episode family story and focus groups in progress to ensure that the series is relatable, engaging, and educational for African Americans with chronic kidney disease, MNITF plans to begin filming in the spring of 2022. We're happy to announce that we recently received a generous grant from the UniHealth Foundation to help with production costs and funding a post-evaluation study of the series. Because producing the series is expected to exceed $1 million, we need your help to make the *Linked by Love* project a reality. You can learn more about the series and how to become a Project Sponsor in this issue.

To increase our national reach and fundraising efforts, we are excited to announce the addition of three new members to the MNITF Board of Directors. Tasked with steering the newly created Fundraising Committee to boost our education and research efforts, Michelle Chaves, Monica Kirchner, and Melissa Grego bring extensive professional and philanthropic experience to their new roles with MNITF. Each of these accomplished women is profiled on the following pages.

As always, we want to thank you for your ongoing support. Together, we can continue to evolve MNITF's mission and increase our efforts to effect change during this pandemic and beyond. We hope you enjoy this issue!

Nicole Mendez
Executive Director

CONTENTS

MNITF’S NEW EDUTAINMENT SERIES

Linked by Love

AN AFRICAN AMERICAN FAMILY STORY ABOUT KIDNEY DISEASE

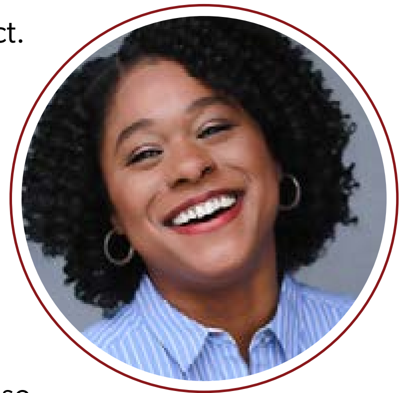
NOW IN PHASE 2 OF DEVELOPMENT

In the U.S., African Americans experience persistent disparities in accessing transplantation, and they have the lowest rates of transplantation from living kidney donors compared to the Hispanic/Lantinx and White populations. In fact, the prevalence of chronic kidney disease (CKD) in African Americans is 25% higher than in White Americans, and they are ten times more likely to develop hypertension-related kidney failure. They are also three times more likely to progress to kidney failure than the White population. Unfortunately, COVID-19 has further emphasized and exposed the significant healthcare disparities that African Americans experience.

Navigating through the many steps involved in the transplant process can also be challenging for African Americans, from education, referral, evaluation, and waiting for a transplant to self-care post-transplant and beyond. Studies show that they’re on dialysis longer than other populations before receiving a referral for a transplant consult, and they generally take longer to complete the evaluation. They’re also less likely to be listed on transplant lists and experience longer wait times once they’re on the transplant list. In addition, they have less access to living donor transplants and have lower rates of graft survival.

To continue its mission of creating engaging, targeted education to meet the needs of vulnerable populations, MNITF began developing its next edutainment series, *An African American Family Story About Kidney Disease*, in 2019. The project, planned for three phases, has made steady progress forward despite the many challenges posed by the global pandemic. Completed at the end of 2020, Phase 1 involved reviewing literature and media sources on the use of scripted narratives for film, television, and web-based media as a health intervention. Phase 1 also included surveying stakeholders, including paired donors and recipients, transplant care providers, content experts, and scripted narrative writers, to develop content that creates awareness and increases the participation of African Americans in paired donation and donor chain efforts.

Armed with data from Phase 1 on relevant themes and storylines for creating the scripts, MNITF began Phase 2 of the project in 2021, with *Linked by Love* as the new title for the series and screenwriter/actor Nicole J. Butler attached as Head Writer. Butler, whose on-camera credits include appearances on *Space Force*, *GLOW*, *The Big Bang Theory*, and many others, created, produced, and starred in the comedic digital series *Sister President*. She also became an internet sensation after her hilarious turn as “She-Shed Cheryl” in a State Farm commercial went viral. Butler has welcomed the opportunity to become involved in the *Linked by Love* project. “At a time of acute upheaval and unrest in the Black American community, this project highlights the importance of self-care in the form of healthcare. Diabetes, hypertension, and toxic stress run rampant through our families to the point that they are often seen as commonplace, yet I rarely hear any mention of CKD until it’s unavoidable,” she said. “The *Linked by Love* project has the ability to empower people by reminding some and educating others that most of the risk factors for kidney disease can be mitigated or even completely eradicated by lifestyle changes.”

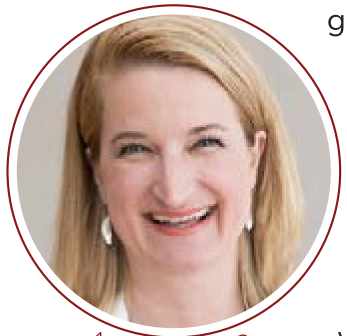

Nicole J. Butler

With scripts for the six-episode series now complete and a cast read-through of the scripts recorded in September via Zoom, the focus group stage of Phase 2 is underway. Butler looks forward to receiving feedback from the focus groups and further refining the scripts before the series moves into production at the end of Phase

CONTENTS

2. “For me, there’s no better feeling than creating fresh, accurate representations of people who don’t always get to see themselves portrayed outside of tired tropes. Representation matters greatly. I’m honored to be a part of the solution and excited for *Linked by Love’s* intended audience to soak it in, cry a little, laugh a lot, and hopefully leave with information that will change the course of their lives,” she said.

Paramount to the success of *Linked by Love* is ensuring that its educational themes, storylines, and characters resonate with those in the African American community who are affected by CKD. The series must also accurately depict the transplant process from a medical perspective. Leading the focus group stage of Phase 2 is Amy Waterman, PhD, who recently became Director of Patient Engagement, Diversity and Education, for the Department of Surgery and J.C. Walter Jr. Transplant Center, Houston Methodist Hospital, and LaShara A. Davis, PhD, Scientist, Houston Methodist Hospital. “Patients often start managing their kidney health and pursuing living donation after they see other people who they trust doing so and benefiting from it,” said Dr. Waterman, who was previously Professor in Residence, UCLA Nephrology. “The focus group research and findings will ensure that we have truly gotten into the world of kidney patients and their family members so that the series can be optimally motivating.” Waterman also sees an even more critical need for targeted education for the African American community due to the pandemic. “Even before COVID-19, African Americans were less likely to receive living donor transplants in every transplant center in the country,” she said. “After COVID-19, we need to redouble our efforts to connect with African American patients to ensure that they have equal access to the best treatments and the best quality of life possible.”


Amy Waterman, PhD

Having to make considerations for COVID is also impacting how the focus groups will be conducted. “In light of COVID, to keep everyone safe, the focus groups will be conducted virtually via Zoom. We will hold one focus group for each of the six episodes and then a single focus group to review the entire series, resulting in a total of seven focus groups,” said Dr. Davis. “Prior to the start of the focus group interviews, we will have participants complete a brief demographic survey. They will also be asked to respond to a series of questions that assess their knowledge about kidney disease and transplant. Participants will then be shown a recording of an episode of the series. After watching the video, they will complete another survey that asks about their knowledge and their enjoyment of and engagement with the storyline.” During the remaining time of each focus group session, Drs. Waterman and Davis will delve deeper into the patient's perspective through group interviews, and ask the group specific questions about the script and the educational information they received. “The focus groups will provide valuable insight into what participants liked/disliked about the episodes, what they felt was authentic vs. inauthentic to the experience of managing life with CKD, and whether or not they found the storyline and characters relatable. The information that’ll come from this focus group will be key to pinpointing the specific changes that can be made to make this series not only entertaining but educational,” Davis said.

Linked by Love read-through with actors (clockwise, from top-left) *Juan Monsalves, Michelle Carter, Byron Newsome, and Carolyn Wilson*

Ultimately, the patient and family perspectives from the focus groups will help MNITF and the creative team improve the scripts before filming the series. Integrating these perspectives improves the likelihood that people will watch the series, engage deeply with the topics, and learn more about CKD and its treatment. Dr. Davis sees this as the best possible outcome. “For patients who have not developed kidney disease but may have hypertension and diabetes, my hope is their lives are impacted by the series in such a way that they engage in new, healthier prevention behaviors and can avoid progressing to kidney disease. For those who have kidney disease, I hope that this series provides them with new tools for considering their different treatment options, namely living donor transplant,” she said. “For family members and friends who engage with this program, I hope they become more open to being evaluated to see if they can be a donor for their loved one who is in need.”


Lashara A. Davis, PhD

Dr. Waterman also hopes that her and Dr. Davis’s work on the focus group study helps the *Linked by Love* project lead to better outcomes for patients and their families. “I applaud MNITF for their creativity and commitment to building this important edutainment series. I read the scripts, and I was touched and moved by the family that is portrayed there. I would love for this episodic series to generate buzz that transplant can be a source of hope for the African American community and that the love of family is always crucial to facing and overcoming health challenges,” she said. “I always say that transplant is the best of healthcare and the best of humanity, and I think this series truly exemplifies that. I’m excited to see what patients and families think of it!”

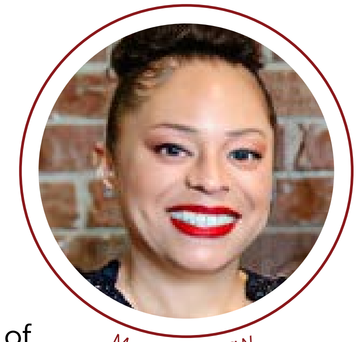
CONTENTS

MNITF Establishes *Linked by Love* Advisory Committee

To help make the *Linked by Love* project a success, MNITF has established a volunteer Advisory Committee comprised of members who have professional expertise or personal experience with kidney disease, kidney failure, transplantation and/or living donation, or are in the entertainment industry. MNITF has carefully selected each member to provide valuable recommendations and guidance, depending on their specific qualifications. Advisory Committee members have been playing an active role in these key areas: script development and review, identifying study participants, identifying celebrity spokespeople, and identifying organizations, churches, and medical community members to help promote the series, build viewership, and support kidney disease awareness and prevention.

Dr. Vincent Anthony

"As one of the few African American nephrologists in the country, I felt it a privilege to offer my expertise on the project. I want people to get a sense of the reality of renal disease. In the African American community, there are many myths surrounding the condition. This project dispels some of those myths. More than that, it tells the truths of renal disease progression," said Vincent Anthony, MD, MPH, SCH, FASN, CPE, CHCQM, Nephrologist, President and CEO, Kidney Care Institute, when asked about his advisory role on Phase 2 of the project. "The most exciting aspect about being involved is knowing that I contributed by helping to infuse clinical truth into the project. By corroborating what was written or adding specific components, I feel that patients and clinicians alike will be able to attest to the clinical authenticity of the project."



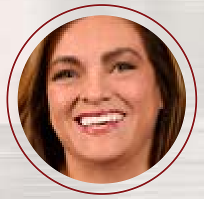
Marci Knox, LCSW

Marci Knox, LCSW, MPH, LCSW, Ronald Reagan UCLA Medical Center, learned about the project through Dr. Jeffrey Veale, Professor, Department of Urology, UCLA Health/Director, UCLA Kidney Transplant Exchange Program. Knox became involved in the *Linked by Love* project during Phase 1. "I was asked by Dr. Jeff Veale to be a part of the project. I was excited to participate and be part of the Advisory Committee because I'm passionate about the mission and the target population," she said. "I think it is important for the target population to understand that we can relate to their fears and mistrust surrounding transplant and healthcare in general. This project was created by individuals who look like them and are passionate about kidney transplant. The most exciting thing about being involved was the experience of working alongside other African American professionals in kidney transplant and hearing the experiences and perspectives of donors and kidney transplant recipients."

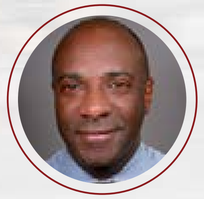
CONTENTS

The *Linked by Love* Advisory Committee is made up of these dedicated individuals:

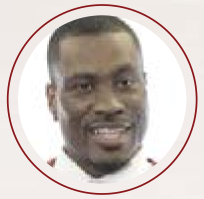
Vincent Anthony, MD, MPH, SCH, FASN, CPE, CHCQM
Nephrologist,
President and CEO, Kidney Care Institute



Nicole Marostica
Vice President, Publicity
Walt Disney Studios



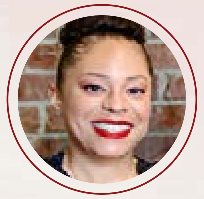
Roberto Vargas, MD, MPH
Assistant Dean, Health Policy and
Inter-Professional Education, College of
Medicine, and, Pillar Director, Urban Health
Institute, Charles R. Drew University



Edward Drake
Transplant Recipient,
Founder and CEO, The Youth Needing
Organ and Tissue Transplants Foundation
(YNOTT?)

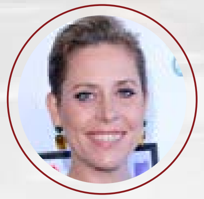
Jeffrey Veale, MD
Professor, Department of Urology,
UCLA Health Director, UCLA Kidney
Transplant Exchange Program

Amy Waterman, PhD
Director of Patient Engagement, Diversity
and Education, Department of Surgery and
J.C. Walter Jr. Transplant Center, Houston
Methodist Hospital



Marci Knox, LCSW, MPH
LCSW, Ronald Reagan
UCLA Medical Center

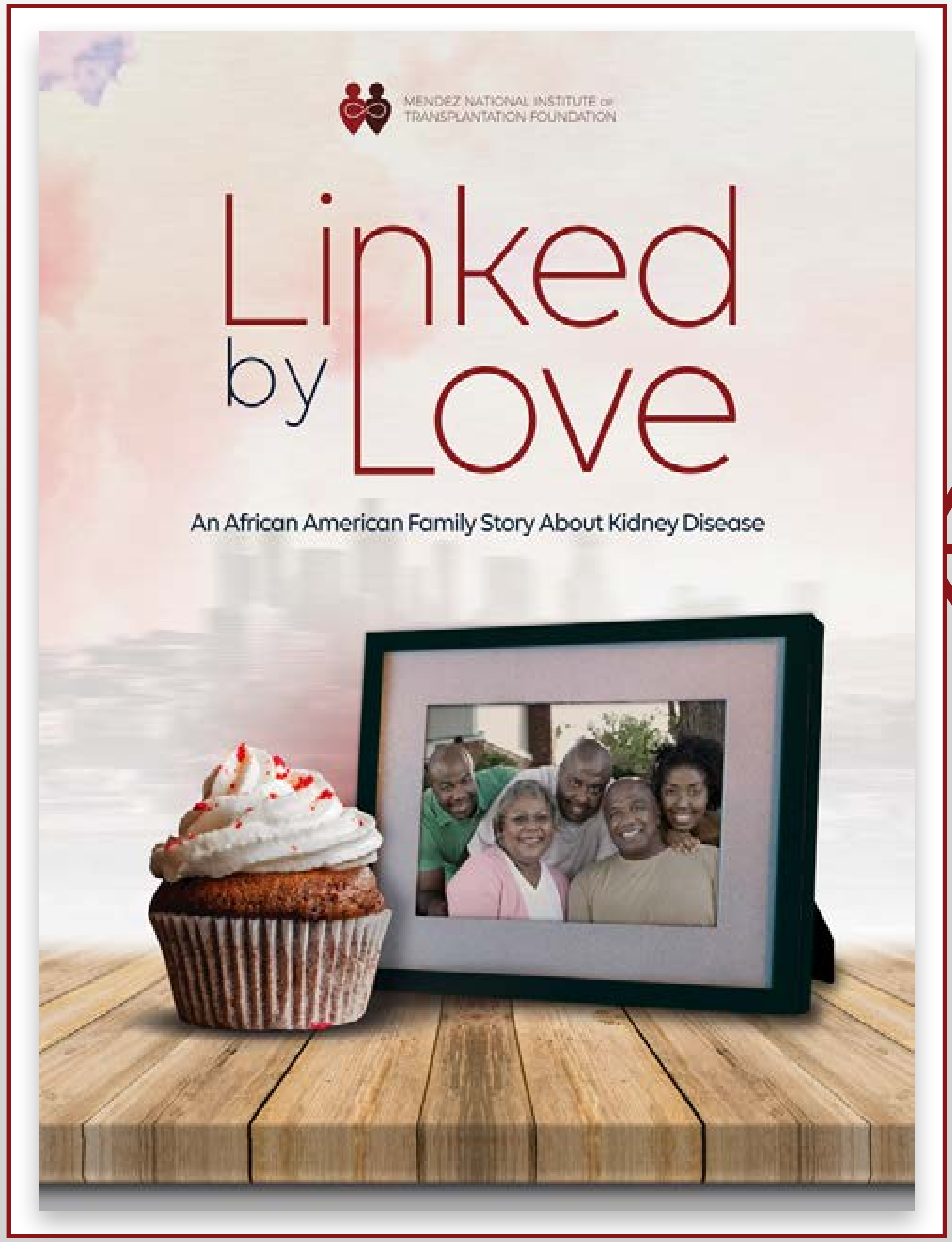
Franco Reyna
Program Manager, National Kidney
Foundation of Southern California and
Southern Nevada



Tenaya Wallace
CEO, Crowd Advocacy
Founder, Donate Life Hollywood

You Can Help Us Tell the Story!

Linked by Love will tell the relatable, culturally relevant story of an African American family struggling with kidney disease. It will also provide targeted education that is desperately needed and long overdue. We hope that you will help us take immediate action in addressing the significant racial and healthcare disparities that exist within the African American population, and consider becoming a Sponsor.



CONTENTS

MENDEZ NATIONAL INSTITUTE OF TRANSPLANTATION FOUNDATION

Linked by Love

An African American Family Story About Kidney Disease

Coming Soon!

Sponsorship Levels

☐ **EXECUTIVE PRODUCER** (maximum of 4) **$100,000**
Credit as Executive Producer (EP) in opening and end credits of episodes, EP credit on IMDb, the world's most popular Film, TV, and celebrity content site; EP credit on MNITF's websites and in newsletter; lunch on set*; and invitation to wrap party *(* see note below)*

☐ **CONTRIBUTING PRODUCER** (maximum of 6) **$50,000**
Credit as Contributing Producer (CP) in opening and end credits of episodes, CP credit on MNITF's websites and in newsletter; lunch on set*; and invitation to wrap party *(* see note below)*

☐ **ASSOCIATE PRODUCER** (maximum of 6) **$25,000**
Credit as Associate Producer (AP) in end credits of an episode AP credit on MNITF's websites and in newsletter; and invitation to wrap party

☐ **CAMEO SPEAKING ROLE** (maximum of 2; one line for each) **$10,000**
Character credit in end credits of episode; listed as a Featured Contributor on MNITF's websites and in newsletter; and invitation to wrap party *(* see note below)*

☐ **WALK-ON-ROLE** (maximum of 2; no lines) **$7,500**
Listed as a Contributor in end credits of episode; listed as a Contributor on MNITF's websites and in newsletter; and invitation to wrap party *(* see note below)*

☐ **CONTRIBUTOR** .... **$10,000–$1,000**
Listed as a Contributor in end credits of series; listed as a Contributor on MNITF's websites and in newsletter

Sponsorship Levels: Your contribution will go directly to the production of Linked by Love, an edutainment project that will provide information to the public about kidney transplantation, living donation, and kidney disease prevention. Your contribution is considered a sponsorship only, and there will be no involvement with actual production. Production is expected to be complete in mid-2022. All contributions are tax-deductible to the full extent of the law; please discuss with your accountant or tax professional. (501c3, Tax I.D. #95-445-0030)

** Due to COVID-19, production may require a negative COVID-19 test. In addition, there may be other restrictions to being present on set.*

I would like to be a Sponsor *(type and amount)* ____________________

I would like to make a donation of $ ____________________

Please list my/company name as ____________________

Name ____________________

Address ____________________

City ____________________ State ____________________ Zip ____________________

Phone____________________ Email ____________________

Checks are payable to: National Institute of Transplantation Foundation

Or, plase charge my ______ Visa ______ Mastercard ______ American Express

Card# ____________________ Exp. Date ______________Security Code ________ Billing Zip ________

Name on Card ____________________ Signature ____________________

Send this form to:

Mendez National Institute of Transplantation Foundation • 2600 West Olive Avenue, Suite 500 • Burbank, CA 91505
For more information, please contact Nicole Mendez at 424.358.4450.

MNITF RECEIVES UNIHEALTH GRANT

TO HELP PRODUCE *LINKED BY LOVE*

AND PERFORM POST-EVALUATION STUDY

MNITF is excited to announce that it has received a $400,000 grant from the UniHealth Foundation for its next edutainment series, *Linked by Love*. Specifically, the grant will help fund filming the project and creating and conducting a post-evaluation study to evaluate the effectiveness of the series in increasing African Americans' knowledge about end-stage renal disease (ESRD). Following the success of the multi-award-winning *Fixing Paco* series, also produced with generous support from UniHealth, *Linked by Love* represents an exciting next step for MNITF in its mission to serve the transplant community, address disparities, and develop non-biased content that can make a difference for vulnerable populations.

Jennifer Vanore, PhD

With a core mission of supporting activities that improve the health and well-being of individuals and communities, UniHealth welcomes the opportunity to support MNITF in producing *Linked by Love* and performing a post evaluation of the series. "Kidney disease is an issue that disproportionally affects the African American community. Projects like this, which address health inequity, are part of our larger strategy to improve population health," said Jennifer Vanore, PhD, President and COO, UniHealth Foundation. "Kidney disease is known as a silent killer because there are few symptoms. The late diagnosis rate is one of the reasons why raising awareness, like this video series, is so crucial."

Filming the series is the final stage of Phase 2 of the *Linked by Love* project. Phase 2 has also included writing the episode scripts, filming a read through of the scripts with actors via Zoom, and performing a focus group study, which is currently underway. With help from the UniHealth grant, production is slated to begin in spring of 2022. Once filming is complete and the series is through post-production, the Phase 3 post evaluation will begin. This is an exciting next step for the *Linked by Love* project because the impact of edutainment on chronic kidney disease (CKD) prevention has never been studied. Phase 3 will involve conducting a randomized-controlled trial (RCT) with 240 African American CKD patients and their caregivers. The goal is to assess the effectiveness of the series compared to standard CKD print education materials on increasing African Americans' knowledge about CKD

CONTENTS

and living donor kidney transplant (LDKT). The RCT will also measure the series' effectiveness in improving their attitudes and increasing their behavioral intent to prevent CKD and pursue transplantation, as well as taking small actions towards CKD prevention and pursuing LDKT.

The ultimate goal of the *Linked by Love* project is to improve overall kidney health and increase access to transplantation for African American patients by presenting much-needed education in an entertaining, relatable way. Phase 3 is critical to the success of *Linked by Love* in making a difference for the African American community. Previous research has shown that print educational resources are less effective for patients from underserved communities, especially those who are less ready to change a behavior or have low health literacy.

Infusing education with entertainment has proven effective in the past in connecting an audience with life-saving information, as evidenced by the success of *Fixing Paco* in educating the Hispanic/Latinx population about ESRD and LDKT. The hope is that the Phase 3 post evaluation shows that *Linked by Love* is no different. "By presenting education as part of a story, we can engage people with characters that help educate them about both prevention and treatment of kidney disease in a way that is not as intimidating or threatening as traditional education may be," said LaShara A. Davis, PhD, Scientist, Houston Methodist Hospital. "This technique may also eliminate challenges that traditional education strategies pose to those with limited literacy."

Leading the Phase 3 evaluation effort is Amy D. Waterman, PhD, who was recently named Division Chief of Patient Engagement, Diversity and Education at Houston Methodist Hospital, and was previously Professor in Residence, UCLA Nephrology. Dr. Davis is also working with Waterman at Houston Methodist. Dr. Waterman's recent move to Houston Methodist is beneficial for the RCT post evaluation because it expands the recruitment area for CKD patients for the study to both Houston and Los Angeles. To help ensure that the recruitment of CKD patients in Los Angeles continues to grow, Waterman is enlisting the efforts of Suzanne Nicholas, MD, PhD, as a new Co-investigator on the project. Dr. Nicholas is an African American tenured Professor of Medicine in the Division of Nephrology at UCLA and chairs the Nephrology Racial and Health Equity Committee.

Suzanne Nicholas, MD, PhD

Thanks to the UniHealth Foundation's support, the input received through Phase 3 will help MNITF ensure that *Linked by Love* speaks to those affected by CKD, ERSD, and the greater transplant community. "We are thrilled to have the support and partnership of the UniHealth Foundation for this extremely important project," said Nicole Mendez, Executive Director, MNITF. "We also appreciate the fact that UniHealth is so involved in the grant process and committed to ensuring that the projects they support are a success." Following completion of the RCT, the research team will analyze and publish the findings of the study. Whether they received the series or printed educational materials, the RCT participants' feedback will be pivotal in helping MNITF shape additional editing choices and tailor marketing and messaging to potential audiences in the future.

After Phase 3, MNIFT will focus on promoting and publicizing the series to boost its impact. *Linked by Love* will be accessible through the MNITF website and YouTube channel and will have its own website. In addition, pursuing distribution via digital platforms like Netflix, cable, and other avenues will help the series reach an even wider audience. Similar to the *Fixing Paco* PSA campaign, *Get the Facts! Get Checked! Get Healthy!*, *Linked by Love* PSAs will be eventually developed to inform the public about kidney disease awareness and prevention and create a call-to-action to view the series. The annual Kidney Awareness Month in March and Organ Donor Awareness Month in April will also provide ongoing opportunities to elevate the series' message and reach.

With the increased focus on racial disparities across many aspects of society, particularly health, the *Linked by Love* project comes at an opportune time. Everyone involved hopes the series will be a welcome addition to the conversation. "MNITF is mission-driven and committed to addressing and ending kidney disease. Their commitment to producing videos that make such complex and difficult health issues more accessible to a range of populations is a timely strategy," said Vanore. "Having as many people as possible watch this series and share it with friends and family would be the greatest outcome." Echoing *Linked by Love*'s title, MNITF and the UniHealth Foundation are linked by a shared dedication to creating life-saving projects that have the power to transform the health of an entire community.

CONTENTS

MNITF ANNOUNCES THREE NEW BOARD MEMBERS

AND THE CREATION OF THE FUNDRAISING COMMITTEE

MNITF is excited to announce the appointment of three members to its Board of Directors (BoD), Michelle Chaves, Melissa Grego, and Monica Kirchner, who will be steering the newly created Fundraising Committee. With backgrounds in various industries in entertainment and media, these new Board members will play a pivotal role in helping MNITF further its fundraising efforts for its next edutainment series, *Linked by Love*. In addition, they will work to increase MNITF's national profile and open up new funding opportunities for the expansion of our education and research activities in service to vulnerable populations.

Justin Dooley, Chairman, MNITF, hopes that long-term, the fundraising committee will help MNITF make a difference in the technology and practice of transplantation. "This is the culmination of our strategic plan to transform the nonprofit from a laboratory operating entity to a larger, more impactful foundation that services a much broader and unmet need in the transplant community," he said. "Their future efforts will help significantly impact underserved communities at the breadth and scale the transplant community requires."

Michelle Chaves

Michelle Chaves's introduction to MNITF came through her father-in-law and dedicated BoD member Alex Chaves. The combination of Michelle's experience in the film and television industry and philanthropy gives her the tools needed to introduce a new generation of MNITF donors to the foundation's important work and best serve the transplant community.

Ms. Chaves's successful career in film and television began after a fruitful mentorship at UCLA with former heads of Sony Studios John Peters and Peter Guber. She gained much experience as she rose through the ranks at such reputable film and television companies as Warner Brothers, Imagine Entertainment, and 20th Century Fox Studios.

While her two children attended the Center for Early Education (CEE), she started down her philanthropic path, volunteering at CEE and chairing the Punky Reggae/Ziggy Marley Gala 2015, which raised $1 million. Continuing with her philanthropic endeavors, she worked with organizations such as the Cambodian Children's Fund, and in 2008, she and her family organized several fundraisers for Rally for Kids with Cancer. Ms. Chaves is an active contributor to her husband's boards, the Los Angeles Library Foundation and the Georgetown Law Board of Visitors, and in 2010, she took a leadership role serving on the board of the Philanthropic Society of Los Angeles (PSLA). Through PSLA, she currently volunteers with Learning Lab Ventures, working with underprivileged Latin families.

While Ms. Chaves has a family connection to MNITF, it was viewing *Fixing Paco* that helped her gain a deeper understanding of what patients and families go through when faced with kidney disease. After attending several MNITF Fashion Show fundraisers, it occurred to her that she also had the power and extensive philanthropic experience to bring in a new group of influential people and donors to support and spread MNITF's message.

Seeing the important need to raise completion funds for *Linked by Love*, Chaves is already working on bringing in new sources for donations. She has organized a shopping event showcasing talented designers Zadig & Voltaire, and she is working with artists like painter Ori Bengal to participate in auction fundraisers.

It's an exciting next phase in Chaves's philanthropic career. "I would like to thank Nicole and the BoD for giving me the opportunity to make a difference at MNITF," she said. "I always like to say, 'If we can each change just one person's life for the better, this world would be a much better place.'"

CONTENTS

Melissa Grego

Melissa Grego was recommended to the BoD by previous Board member Andy Friendly. She brings unmatched expertise in entertainment and business journalism and looks forward to connecting with those who share the same passion for MNITF's mission.

Communication and connection have been constant themes throughout Ms. Grego's career. She excelled as a television industry journalist, leading her to launch her consulting practice, Melinc, where she executive produced several TV and media industry conferences. In 2017, she became CEO of the nonprofit membership organization the Hollywood Radio & Television Society (HRTS). Under Grego's direction, HRTS continues to be recognized as a leading information and networking forum within the TV, media, and entertainment industries and is a source of community and conversation with its mentoring, events, and other global initiatives.

Grego thrives on connecting people and sees the main focus of the MNITF Fundraising Committee as one that will broaden the potential base of supporters and further spread the word about MNITF. Her personal goal in her new position on the BoD is to contribute and practice her skills in strategy, communication, event production, and cultivating support. "The way people do business, interact, and decide how to lend support is all ripe for a rethink," she said. "This is an opportune time to build on what and how we do so well and uncover new areas for growth." She is excited to get to know her fellow committee members and to together make an impact at MNITF, with the *Linked by Love* project, and in the transplant community as a whole.

CONTENTS

Monica Kirchner

MNITF greatly benefits from appointing long-time supporter Monica Kirchner to the BoD. Ms. Kirchner is the daughter of Sonia Randazzo, who spearheaded MNITF's celebrated *Couture for a Cause* Fashion Show fundraiser for many years. She is excited to continue her family's legacy of service to MNITF.

Drawn to MNITF's mission of improving the lives of those in the transplant community, Ms. Kirchner brings a wealth of experience in fundraising, both professionally as a former corporate attorney and as an investment banker at Lehman Brothers. Additionally, she has served on education and medical research nonprofit boards, including the Ahmanson-Lovelace Brainmapping Research Center Board at UCLA.

With her strong legal and business background, Ms. Kirchner is a dynamic force in the startup space. A talented and driven executive, she is currently the co-founder and CEO of Luxury Partners, LLC, which owns and operates the ".luxury" domain and serves as a hub for all things luxury for consumers and manufacturers. Kirchner has continued to make a name for herself in the luxury space by launching iLux Media Group, a media company dedicated to helping consumers discover luxury items. Additionally, she co-founded Luminare Labs, a startup that focused on cutting-edge brain imaging technology.

Ms. Kirchner is looking forward to growing MNITF's fundraising efforts and supporting its overall mission and is especially excited by MNITF's new approach to having a dedicated Fundraising Committee within the BoD. She understands the inherent relationship between evolving medical science and the funds that support and sustain the research's success. "I am proud to share a common passion and purpose that MNITF represents," she said. "I am greatly looking forward to enhancing my knowledge of organ transplantation research and being a small part in helping to improve the lives of organ transplant patients and their families."

MNITF looks forward to working with Michelle Chaves, Melissa Grego, and Monica Kirchner. They bring passion, commitment, and the shared goal of improving the lives of those within the transplant community and making a difference.

In Memoriam:

Remembering James “Jim” Schellenberg

(1954–2020)

On December 9, 2020, Jim Schellenberg, MNIT’s first Chief Operating Officer (COO), passed away at his home in Pacific Palisades, California, after an extended battle with cancer. Jim’s passing leaves a tremendous void for his family and community, but he also leaves behind an unparalleled legacy of leadership excellence and devotion to serving others.

Jim earned his bachelor’s degree at Vanderbilt University, where he also played football, and received his MBA from the University of North Florida. A healthcare executive before joining MNIT, Jim became COO on March 10, 2003. “My background in health care provides several components to the Institute, and my task is to see that there is coordination among each of them: increased donor awareness, patient and public education, research, laboratory testing, and data management. One might add public relations and fundraising to the mix,” he said at the time. “I believe my experience will allow me to implement some internal processes that allow people and organizations to measure their success against a standard and will set the stage for NIT to exceed that standard.”

During his tenure, Jim helped usher in a new phase of organizational growth that allowed MNIT extend its reach and its ability to support the transplant community. His efforts continue to make an impact. “Jim built the HLA lab, and he created a program in the serology lab to help all the organ procurement organizations get rapid NAT tests to help make sure organ donations were safe,” said Justin Dooley, Chairman, MNITF. “By building the HLA lab and expanding the serology lab into a molecular lab, he helped create the value that was realized ($10 million) when we sold those labs, which has helped secure the foundation, MNITF.”

Pictured: (clockwise from top-left)
Katie, Debra, and Jim Schellenberg

Jim’s leadership vision for MNIT and his dedication to furthering its mission were also profoundly personal. “I have a particular interest in this field because my brother had a rare liver condition and waited five years for a new organ, through a number of critical episodes and hospitalizations,” Jim once shared. “He eventually received his transplant at the Mayo Clinic in Jacksonville, Florida, and now is healthy as one can be. I have a large family, with five brothers and five sisters. The experience with my older brother energized all of us, and we have all signed donor cards.” Along with his family, Jim worked to share knowledge about his brother’s illness and raise awareness about the need for donors, leading to nearly 200 additional people signing donor cards.

CONTENTS

Maralyn Dooley, wife of Justin Dooley and a living donor for her sister Madalyn Minch, remembers the extraordinary depth of Jim's personal connection to those undergoing end-stage renal disease and transplant. "I have so many wonderful memories of Jim helping my sister, Madalyn," she said. "There was a day when my sister, who was legally blind, needed some immediate medical treatment. Jim walked her into the ER, and literally held her hand during the consult. On another occasion, Madalyn was having a health difficulty, and Jim personally contacted the right members of her medical team and waited with her until she got things resolved. There was no one else like him!"

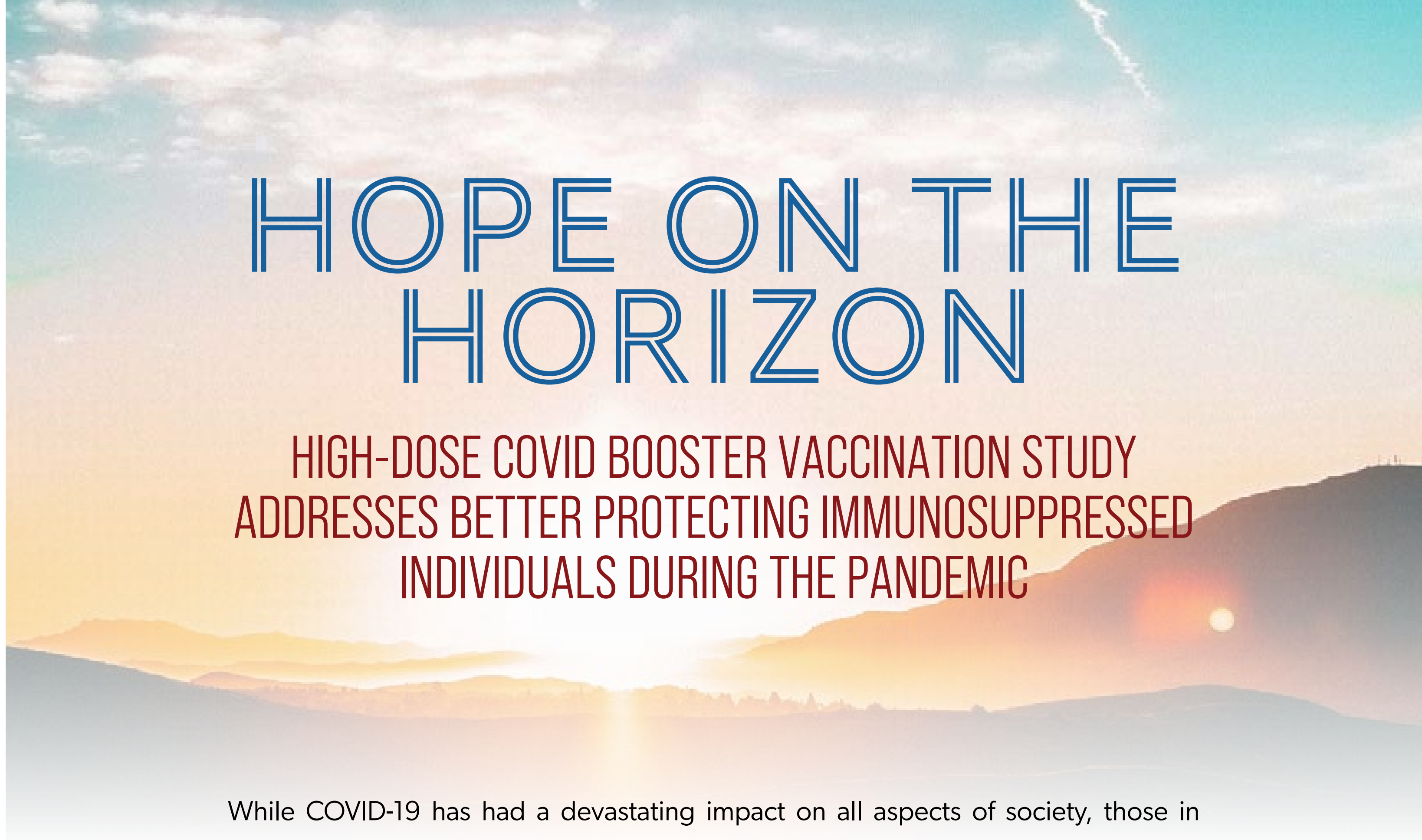
A passion for compassionate service, personal excellence, and most importantly, his family, were hallmarks of Jim's life. Jim's son, CJ Schellenberg, remembers his father as someone who made the most out of his life, right up to the end. "From the moment my father was diagnosed with his aggressive illness, he was at peace. He knew that no amount of complaining, stress, or dismay would change anything about his unfortunate predicament. This is a quality that I believe everyone should strive for, not complaining about the hand you are dealt, but being thoughtful in how to play that hand," he said. "My father did not waste his final days wondering *what if* or saying *woe is me*. Instead, he used his final months and days to enjoy himself. He was able to spend time with and enjoy the time with his wife, friends, his children, and grandchildren. I am at peace knowing that his strength will live on through the lives that he touched."


Pictured: Jim Schellenberg with CJ Schellenberg and children

Jim is survived by his wife of 40 years, Debra Schellenberg; his daughter, Kathryn Schellenberg Bell; his son, Christopher "CJ" Schellenberg; his son-in-law, Jason Bell; his daughter-in-law, Kristen Schellenberg; and his three grandsons, Wyatt, Beau and Theodore Schellenberg. He is also survived by his 10 siblings, their spouses, and their children.

"We are what we repeatedly do. Excellence, then, is not an act, but a habit."

— Will Durant, Author,
The Story of Philosophy



HOPE ON THE HORIZON

HIGH-DOSE COVID BOOSTER VACCINATION STUDY ADDRESSES BETTER PROTECTING IMMUNOSUPPRESSED INDIVIDUALS DURING THE PANDEMIC

While COVID-19 has had a devastating impact on all aspects of society, those in vulnerable populations are still most acutely affected. The pandemic has cast an unfortunate light on healthcare disparities for many groups, and transplant recipients are among those who are impacted. In fact, they find themselves in a paradoxical situation. To ensure their continued health after transplant, they must maintain a consistent regimen of immunosuppressant medications to guard against rejecting their transplanted organ. But the lifesaving act of taking these medications also means that a recipient's ability to build immunity via vaccinations against SARS-CoV-2, the virus that causes COVID-19, is drastically reduced.


Marcia Goldberg, MD

The MNITF Research Grant Program (RGP) has been at the forefront of rapidly addressing the effect of COVID-19 on the transplant community and funded two COVID-related grants in 2020, at the height of the pandemic. Continuing its effort to meet the unique needs of the transplant community around COVID-19, the RGP has recently awarded a $150,000 grant to Marcia Goldberg, MD, of Massachusetts General Hospital, for the *Efficacy of High-Dose Booster Vaccination in Vaccine Non-responsive Immunosuppressed Individuals* study. The project, which will test whether a high-dose booster vaccination enhances the protection of immunocompromised individuals against COVID-19, has the potential to make a significant difference for transplant recipients during the pandemic.

CONTENTS

Studies have shown that heart and lung transplant recipients, who are heavily immunosuppressed, respond poorly to standard SARS-CoV-2 vaccination regimens. To address this, the high-dose booster vaccination project will test whether a third dose of vaccine that consists of twice the amount of immune stimulus produces better immune responses than a third dose in standard amounts, by assessing antibody and/or cellular immune responses in transplant recipients. “Organ transplant recipients typically take several immunosuppressive medications to keep their bodies from rejecting the transplanted organ. Consequently, transplant recipients are significantly ‘immunosuppressed,’” said Dr. Goldberg. “Studies show that because of their immunosuppression, a quarter to three-quarters of transplant recipients did not develop immune responses after the standard primary series of the COVID-19 vaccination. Since antibodies are one of the major ways our body protects us from COVID-19 infection, these individuals are poorly protected and at higher risk of developing COVID-19, including severe COVID-19.”

The study involves comparing levels of spike protein and receptor-binding domain IgG and IgM, pseudovirus neutralization activity (parental and emerging variants), antigen-specific T cell activation, and antigen-specific plasmablast and memory B cells to those of matched non-boosted individuals. “In layperson’s terms, ‘IgG and IgM’ are types of antibodies that are found in the blood. We will assess the level of these antibodies that specifically recognize the COVID-19 virus,” Goldberg explained. “‘Pseudovirus neutralization activity’ is how we measure whether these antibodies block the COVID-19 virus from entering human cells, so it’s a measure of how well the antibodies protect against infection. ‘Antigen-specific T cell activation,’ and ‘antigen-specific plasmablast and memory B cells’ are measures of the cellular immune response, which works together with antibodies to protect us from infection.”

To conduct the study, Dr. Goldberg and her team will screen heart and lung transplant recipients who are followed at Massachusetts General and those who are interested in participating in the study. All participants will be screened, and those who have little or no antibody to the COVID-19 virus will be consented and enrolled. “They will be randomized to receive either the standard dose of Moderna booster or twice the standard dose,” said Goldberg. “After receiving the booster, we will collect blood samples at predefined intervals and analyze those blood samples for immune responses to the booster.” According to Dr. Goldberg, there are currently no official recommendations on which vaccine is best for transplant recipients. Although transplant recipients have not been evaluated on a large scale, recent data indicates that in several populations of people, the immune response induced by the Moderna mRNA vaccine is better than that induced by the other vaccines currently available in the U.S.

A Goal: Improving Life for the Immunocompromised During the Pandemic

Because they may lack vaccine-induced immunity to COVID-19, transplant recipients essentially need to behave as if they’re unvaccinated. For many, this means remaining masked in all indoor settings, not eating indoors at restaurants, and avoiding sharing meals with any individuals who are not in their household or “bubble.” Family members of transplant recipients are also affected because even if they’re vaccinated, they can still spread the Delta variant of COVID-19. Thus, family members of transplant recipients also need to behave as if they’re unvaccinated to help protect their transplanted family member. Maintaining this heightened level of caution can create a strain on transplant recipients and their families and impact the quality of life for everyone involved. “The most positive outcome possible for this study would be if a higher dose of vaccine induces immune responses in 100% of the transplant recipients who receive it,” said Goldberg. “Our goal is to find approaches that improve COVID-19 vaccine-induced immunity among transplant recipients, to enable them to return to more normal lives.”


Camille Kotton, MD

Determining whether a high-dose or standard-dose booster vaccination to SARS-CoV-2 significantly improves protection for transplant recipients is the goal for Dr. Goldberg and her team. They hope to advance scientific knowledge to better protect transplant recipients against COVID-19 infection and directly improve future clinical outcomes in transplantation. Goldberg is grateful for MNITF’s support of the study and the dedicated efforts of all involved. “I could not do this without my team, Drs. Jacob Lemieux and Camille Kotton, both of Massachusetts General Hospital. Nor could we do this except for the extraordinary generosity of the transplant recipients who participate in this work.”


Jacob Lemieux, MD

CONTENTS

THE NEXT GENERATION OF ADVANCING THE SCIENCE AND PRACTICE OF TRANSPLANTION:

MNITF FUNDS TWO STUDIES FROM EARLY-STAGE INVESTIGATORS

The MNITF Research Grant Program (RGP) has a strong legacy of supporting the work of promising young investigators to help continue its mission of innovating solutions and advancing the science and practice of transplantation. This year, the RGP funded two grants by early-stage investigators, *Delineating the Biological Mechanisms of Graft Fibrosis in Liver Transplant Recipients* and the *Molecular Characterization of Baseline Lung Allograft Dysfunction*. In partnering with MNITF, both projects aim to reduce the knowledge gap and make a difference in advancing transplantation-related research that creates better outcomes for transplant recipients.

CONTENTS

Mamatha Bhat, MD

Extending the Liver Graft's Life Span

Mamatha Bhat, MD, is Clinician-Scientist and Staff Hepatologist at the University Health Network, Toronto, and received a $150,000 grant for her study. She has had extensive collaborations with machine learning and bioinformatics experts, which brings many different perspectives to her work. Dr. Bhat's research is directed at enhancing long-term survival in liver transplant recipients by focusing on preventative and therapeutic strategies to reduce complications after transplant.

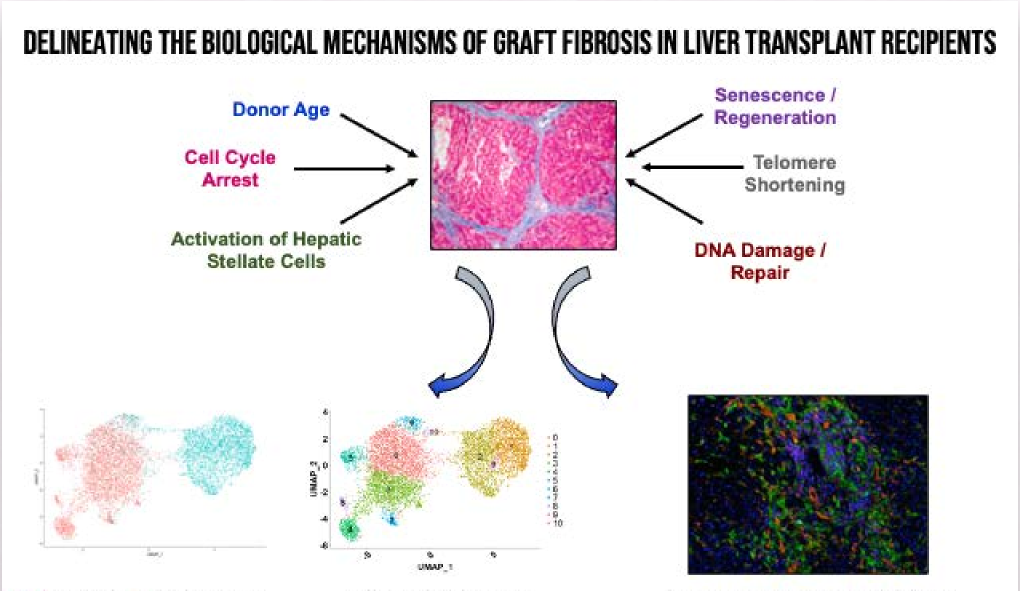
"The life span of the transplant is finite," said Dr. Bhat. "Of those patients who receive liver transplants, 80% generally live for at least five years, but their long-term survival can be compromised by scarring (fibrosis) development. It's not fully understood why fibrosis accumulates faster in the graft than in the native liver."

The goal of Dr. Bhat's research is to extend the life span of the transplanted liver by better understanding the obstacles that arise after transplantation. For instance, graft fibrosis develops in the setting of recurrent or de novo disease. Hepatitis C used to be the main reason for graft fibrosis, and now that it has become curable with antiviral therapy, it has been supplanted by recurrent non-alcoholic steatohepatitis (NASH). Additional causes of ongoing inflammation leading to fibrosis include recurrent autoimmune liver disease, repeated episodes of rejection, and biliary disease. These difficulties highlight the need for further understanding about how these factors lead to graft fibrosis and ultimately graft loss.

"In this study, we will examine liver samples after transplant to understand the contribution of graft age, capacity to regenerate, and activity of cells that accelerate scarring," Bhat explained. "We will use techniques to characterize cell types and signaling pathways that drive fibrosis. These findings will provide insight into therapeutics to prolong graft survival."

In addition to studying the liver after transplant, evaluating the liver donor is another aspect of the project. Factors like the donor's age or immunosuppression regimen play an active part in determining how the native liver will respond to the graft and the ability of the transplanted liver to regenerate.

Dr. Bhat and her team are grateful for the opportunity provided by the MNITF RGP. "We'd like to thank MNITF for their support of our project," she said. "We hope that the results will enlighten our understanding of the mechanistic basis of graft fibrosis, thereby informing potential therapies to increase graft life span."



CONTENTS

Kieran Halloran, MD

Breathing New Life into Lung Transplant Research

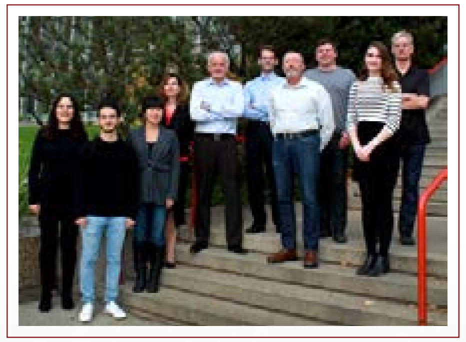
Kieran Halloran, MD, MSc, is an Associate Professor and academic physician specializing in lung transplant medicine at the University of Alberta and the recipient of a $147,695 MNITF RGP award for his study at the Alberta Transplant Applied Genomics Center.

Dr. Halloran's research is a continuation of the work of his father, Dr. Phillip Halloran, who is a Professor of Medicine at the University of Alberta and the 2020 recipient of an RGP award. Through the senior Halloran's grant, MNITF provided generous support for the Molecular Microscope® Diagnostic System (MMDx), aiding in studying the molecular characterization of lung rejection and chronic lung allograft dysfunction (CLAD).

Academics in the lung transplant community have heavily researched CLAD. But that focused attention has not addressed the issues of the subtype of post-transplant lung dysfunction known as baseline lung allograft dysfunction (BLAD), where lung function after transplant fails to reach normal levels. Prior research with CLAD benefits both future studies for BLAD and the lives of lung transplant recipients, so Dr. Kieran Halloran and others are pushing to expand the conversation and bring BLAD to the forefront.

Currently, lung transplant recipients have an average life expectancy of six years after transplant. With BLAD, the function of the transplant after surgery ("baseline") is below the level it needs to be to perform well. Despite having a transplant, patients with BLAD are still afflicted by shortness of breath or have an increased risk of dying. Halloran hypothesizes that if tissue damage can be observed on the molecular level, clinicians can track changes, treat damage, and develop new preventative measures.

Many things can contribute to a transplanted lung becoming damaged. If the donor was older or smoked significantly, that can lead to lung dysfunction. A patient's immune system will also recognize a transplant as foreign to the body and attack the lungs, causing rejection and damaging the lungs in the process. There are ways to reduce the risk of rejection by suppressing the immune system with medications, but this increases the risk of infection, which damages the lungs. Even acid reflux from the stomach puts the lungs at risk by spilling over into the airways. Thus, researchers have to examine many factors to determine the cause of dysfunction. Comparing lung biopsies between transplant recipients with poor post-transplant function to those with normal function using the MMDx will help Halloran and his team highlight areas for investigation and get closer to determining prevention and therapeutic solutions.



Pictured: The team at the Alberta Transplant Applied Genomics Center

By understanding the types of cells involved when damage occurs, through using biopsy-based tests, researchers can determine if problems stem from the lung tissue itself, and to what extent, and determine what lung-function treatments are possible. Halloran also hopes this study starts a broader conversation about investigating this type of lung dysfunction among academics in the lung transplant community and sparks the interest of other investigators and scientists to study it.

With MNITF's support, Dr. Halloran hopes the conversation about BLAD takes root and that he and his team can significantly contribute to the knowledge base around lung transplant physiology. "It's difficult to measure the enormous impact of MNITF at the patient level," he said. "But the work that they have supported over the years and continue to support has undoubtedly materially contributed to saving and improving countless lives."

For its part, MNITF looks forward to supporting more early-stage investigators like Dr. Halloran and Dr. Bhat through the RGP. "Every year, we are fortunate to have many talented researchers come to MNITF with life-saving studies in the field of transplantation," said Nicole Mendez, Executive Director, MNITF. "We are excited to support the next generation of researchers and partner with them as they progress in their careers."

CONTENTS

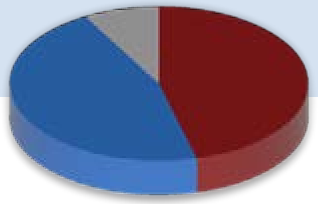
RESEARCH GRANT PROGRAM AWARDS 37 GRANTS

In December 2014, MNITF launched the Research Grant Program to improve clinical outcomes and positively impact the field of transplantation. To date, MNITF has awarded 37 grants, both nationally and internationally, surpassing $3 million. The Research Advisory Board is comprised of senior investigators and experts in transplantation research who review the grant proposals and provide recommendations to the MNITF Board of Directors, who then make the final decision on awarding each grant. Due to the number and high quality of submitted proposals, the Board has awarded more than the budgeted amount from the Endowment. Contributions to the MNITF from supporters have made this possible.

Priority Area of Research

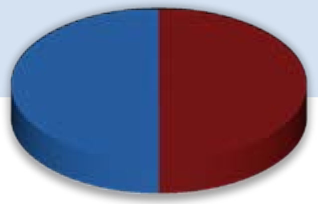
Selection and Screening	8	21.6%
Organ Quality Assessment and/or Enhancement	3	8.1%
Organ Recipient Related and/or Post-Transplant Monitoring	13	35.1%
Patient Education and Empowerment	3	8.1%
Organ Repair and Regeneration	7	18.9%
COVID-19	3	8.1%
Total	**37**	**100.0%**

Organs, Recipients & COVID-19



Organs: Procurement & Generation	17	46%
Recipients: Pre- and Post-Transplnt Issues	17	46%
COVID-19	3	8%
Total	**37**	**100%**

Early and Senior Investigations



Early Investigator	16	50.0%
Senior Investigator	16	50.0%
Total	**32**	**100.0%**

Grant#	Organization & Location
1	Viracor-IBT Laboratories, Los Angeles, CA
2	Viracor-IBT Laboratories, Los Angeles, CA
3	Donor Network Wes, San Ramon, CA
4	The Ohio State University, Columbus, OH
4a	University of Massachusetts Medical School, Worchester, MA
5	Viracor-IBT Laboratories, Los Angeles, CA
6	John Hopkins University, Baltimore, MD
7	Massachusetts General Hospital, Boston, MA
8	Massachusetts General Hospital/Harvard Stem Cell Institute, Boston, MA
9	Western University of Health Sciences, Pomona, CA
10	Viracor-IBT Laboratories, Lee's Summit, MO
11	University of Miami, Miami, FL
12	Joan & Sanford I Weill Medical College of Cornell University, New York, NY
13	Viracor-IBT Laboratories, Los Angeles, CA
14	The Scripps Research Institute, La Jolla, CA
15	University of Alberta, Edmonton, Edmonton, Alberta, Canada
16	Brigham & Woman's Hospital, Boston, MA
17	University of California, San Francisco, San Francisco, CA
18	Massachusetts General Hospital/ Harvard Medical School, Boston, MA
19	Cornell University, New York, NY
20	University of Alberta, Edmonton, Edmonton, Alberta, Canada
21	UCSF, San Francisco, CA
22	UCLA - David Geffen School of Medicine, Los Angeles, CA
23	Centre Hospitalier Univeritaire Vaudois, Lausanne, Lausanne, Vaiud, Switzerland
24	Charles R. Drew University of Medicine and Science, Los Angeles, CA
25	IVIVA Medical Inc., Beverly, MA
26	University of Pennsylvania, Philadelphia, PA
27	Brigham & Women's Hospital, Boston, MA
28	United Network for Organ Sharing, Richmond, VA
29	Columbia University, New York, NY
30	Massachusetts General Hospital, Boston, MA
31	University of Alberta, Edmonton, Edmonton, Alberta, Canada
32	The Regents of the University of California on behalf of San Francisco Campus, San Francisco, CA
33	IVIVA Medical, Inc., Beverly, MA
34	Columbia University Medical Center, New York, NY
35	Massachusetts General Hospital, Boston, MA
36	Univerity of Alberta, Edmonton, Edmonton, Alberta, Canada
37	Univerity Health Network, Toronto, Ontario, Canada

CONTENTS

WAYS TO GIVE

The Gift of Making a Difference

You can be an important part of continuing the mission of MNITF and helping to save and improve the lives of so many. Financial giving to MNITF creates unique opportunities for us to devote necessary resources to further advancing research and education. Below is a list of ways that you, your family, and friends can help keep the flame of hope alive for potential transplant recipients.

Directed Giving

With a planned giving strategy, you can earmark your contribution for any area of MNITF's work that you choose, including the Research Grant Program and Education projects.

Life Income Gifts

The most common type of life income gifts are charitable gift annuities and charitable remainder trusts.

Gift of Cash

This is the simplest and most common type of support. You can make a one-time gift, monthly payments, or pledge to donate over a one- to five-year period.

Life Insurance

Donating a no longer needed policy entitles you to an immediate tax deduction for the policy's current cash value. This applies to whole life and not term life insurance policies.

Memorial or Honorarium Gifts

This is a gift made in memory of, or in honor of, a loved one. A notification of your gift, with the amount undisclosed, is sent to the recipient indicated.

Bequests

You can provide a donor's estate with a charitable deduction to offset federal taxes.

Amazon Smile

The Amazon Smile program allows you to donate 0.5% of all of your purchases on Amazon to MNITF. Go to **smile.amazon.com**, sign in with your Amazon account, and then search for National Institute of Transplantation as your charitable organization.

The MNITF website (www.MNITF.org) allows you to donate with a credit card by clicking on ♡ near the bottom of the homepage. If you would like to discuss giving, please contact Nicole Mendez, Executive Director, at (424) 358-4450 or via email at Nicole@MNITF.org.

WANT TO MAKE A DIFFERENCE IN THE LIFE OF SOMEONE WHO IS SUFFERING FROM KIDNEY DISEASE OR KIDNEY FAILURE?

MAKE A TAX-DEDUCTIBLE DONATION OF ANY AMOUNT TO SUPPORT *LINKED BY LOVE.*

1

Text the word KIDNEY to 21000

to make a tax-deductible donation of any amount to MNITF!

2

Go to MNITF.org and click on ♡

3

PayPal

Scan. Pay. Go.

Your generosity makes our work possible!

WANT TO GO GREEN?

To receive the MNITF magazine via email, visit **MNITF.org**, select News, and then Newsletter Sign-Up.

Editor: Nicole Mendez
Writer: Stephanie Wiand
Contributor: Justin Dooley
Layout Design: Little Men Roaring, LLC