VINCENT’S FALLEN SENSE ON COMMUNICATION

In this issue, we put Melissa Cousino in the spotlight as it delivers to us the difficult role of a transparent, candid, sensitive understanding, compassionate and most importantly a truthful conversation about pain, suffering and dying when death is on the horizon in our pediatric population. This is a must read for the IHSLT which can easily apply to our adult population, thank you. Brittany Rhoades recapitulates the role Steve Jobs has had on the ISHLT to improve our skills at making communication endure, that is – writing to publish. It is Linda Staley who gives us the truth of Gustav Stiehl and destination therapy for over 3180 days longer and counting. Next, we have Erin Wells bluntly and appropriately advising us in her must read “Showing Up” is all it takes. Think about it, perhaps among the best forms of communication is just being there without saying a word, especially in the most trying times. Finally, Monica Horn nudges our heart on a glance back to where we have come from two decades ago.

Oh and be sure to have a look into the Editor’s Corner.
IN THE SPOTLIGHT: “I didn’t know this could happen:” Discussing Difficult News with Pediatric Transplant Patients

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Just days before she died, an adolescent lung transplant recipient who experienced a brain hemorrhage a few months post-transplant, wrote six words to me, “I didn’t know this could happen.” Prior to transplant, the risks and benefits, including potential for death, were reviewed in detail with her parents. Her family lovingly asked that the team remain positive and optimistic in her presence. During a time of relatively good health, she herself stated that she was comfortable with any decisions her parents made for her. She preferred that her parents be given the detailed information about her medical course and treatment. However, post-transplant, in the midst of a tumultuous recovery course, including an inability to speak due to a tracheostomy, she began to withdraw and show increased signs of anxiety and distress. Her family and medical team remained optimistic in her presence. They worried that speaking of death and dying now would only make her more worried and depressed. She died without having engaged in conversations about prognosis, advance care planning, and her end-of-life wishes.

Survival rates for children and adolescents with end-stage organ diseases have increased over the past decade [1,2]. Despite these notable improvements, life-threatening complications and mortality still occur in pediatric transplant recipients. For example, 1 in 10 pediatric heart transplant recipients will die within one year of transplantation. With a median survival of 14 [3] years, a subset of heart transplant recipients transplanted in childhood will require re-transplantation before they even reach their 18th birthday. Unfortunately, re-transplantation is associated with even greater risk of mortality [3]. In addition, pediatric patients with organ failure are also likely to receive invasive interventions at the end of life. For example, the majority of children with advanced heart diseases (i.e., non-transplant specific) die in intensive care settings. Approximately 50% of them receive highly technical interventions, such as extracorporeal membrane oxygenation, near time of death. An even greater number (86%) receive mechanical ventilation within their last day of life [4]. Despite similar survival rates to other high-risk pediatric illness populations, the end-of-life care needs of children and families with end-stage organ disease and/or solid organ transplant history are poorly understood [5]. As we care for our pediatric and young adult transplant population, increased understanding of their preferences, values, and needs is imperative. The 2014 Institute of Medicine (IOM) report, Dying in America: Improving Quality and Honoring Individual Preferences Near End of Life, [6] highlighted a critical need for “increased understanding of ways to improve participation in effective advanced care planning and shared decision making among patients and families, including seriously ill children and adolescents, who may be able to participate actively in their health care decision making throughout their lives and as they approach death, and receive medical and related social services consistent with the values, goals and informed preferences.”
Due to the variable course of organ failure with periods of both stability and acute on chronic decompensation, determining the appropriate timing for conversations of this nature can be very difficult, as evidenced by the case discussed in the opening paragraph. However, across the chronic illness literature, youth involvement in difficult conversations related to their prognosis and treatment decisions has been found to be associated with improved health and psychosocial outcomes. Despite these favorable associations, the majority of youth with serious illnesses report feeling inadequately informed and insufficiently involved in treatment-related decisions [7-8].

With funding provided by ISHLT and Enduring Hearts, Dr. Cousino and her research team are working to characterize the unique communication and decision making preferences of pediatric and young adult heart transplant populations specific to prognostication, advanced care planning and end-of-life decision making. Initial findings from this study will be discussed during a sunrise symposium at the 2017 Annual Meeting in San Diego. This pilot data will provide the foundation for the development of an evidence-based intervention to increase youth communication and decision making involvement throughout the course of organ failure with concurrent study of its impact on health-related and psychosocial outcomes over time. The overall objective of this work is to meet the needs of our pediatric patients at risk of shortened life-expectancies with acute appreciation of the challenges parents and providers face related to having these difficult conversations.

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“Real Artist Ship” – Steve Jobs

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Fall has officially begun! There are two things that are almost guaranteed during this time of year: The leaves will not change color in Texas and Apple Inc. will be holding a spectacular launch event to showcase products with capabilities that we never knew we needed, but soon cannot live without. Regardless of your mobile device preference, the Apple release typically stirs a reasonable amount of curiosity for all.

In 1983, Apple Inc. launched the first Macintosh computer. I highly doubt the company or creators were envisioning the iPhone 7 that would come 33 years later. However, the Macintosh and the company’s “Think Different” mantra was the beginning of something spectacular. It’s hard to imagine Millennials answering phones that still sing Hello Moto. Not only have Apple products strongly shaped current culture, but also society has loosely coined the post millennial youth the iGeneration.

Have you ever stopped to think about the magnificent products or ideas that were conceptualized, but never fully developed? Steve Jobs held a fundamental principle about the production and process of Apple products: “It’s not done until it ships” [1]. Imagine where we would be today had Jobs only envisioned the Macintosh computer or iPhone, but never designed the product. Just as devastating, what if he had developed prototypes but never released the product worldwide?

Transplant and VAD multidisciplinary team members are producing incredible new ways to enhance the patient experience and quality. Clinicians live in a time when there are exciting new technologies in order to assist with almost any challenge that arises. Due to increasing complexities of patient care, the Institute of Medicine (IOM) proposed clear guidelines that nurses engage in lifelong learning [2]. Nurses and allied health care professionals alike have risen to the IOM’s challenge and continue to achieve phenomenal patient care goals. The missing component of the IOM’s recommendation is, “It’s not done until it ships”, which translates in healthcare to, “It’s not done until it is published.”

There are numerous benefits to writing for professional publication. Most importantly it provides the healthcare clinician an avenue to share valuable wisdom and insight for patient care. Writing for Nursing Publication guides the novice writer through each stage of the writing process from “Preparing to write” to “Final paper through publication” [3]. In addition to guidance for the writing process, the book provides insight into journal selection and types of article are provided.

For clinicians that prefer more of a traditional learning framework but lack the ability to commit to a weekly classroom setting, there are online open courses. The University Of Utah School Of Nursing offers a “Writing for Professional Journals” open course that can be completed online at the convenience of one’s own schedule and free [4].
Despite the best tools and references, writing for publication can feel daunting to even the most expert clinician; however, there are many great references available to assist with the process. Mentorship is an excellent way to gain experience in writing abstracts and writing for professional publication. Writing with a mentor or published author allows the novice writer to gain expert advice and reduces the barriers often encountered with the writing process. It partners the expert clinician with the expert author in order to achieve successful publication.

There’s no better way to start the writing process than through abstract submission. Writing an abstract allows one to gain valuable writing skills. Poster and podium presentations are excellent opportunities to further develop abstract writing and oral presentation skills. ISHLT 2017 Call for Abstracts is currently open for submission through: October 25, 2016, 11:59 pm, EDT. To find additional information on abstract submission visit http://www.ishlt.org/ContentDocuments/ISHLT_Call4Abstracts_2017.pdf [5].

Disclosure statement: The author has no conflicts of interest to disclose.

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5. ISHLT. "Call for abstracts: thirty-seventh annual meeting and scientific sessions April 5-8, 2017." International Society for Heart and Lung Transplantation, www.ishlt.org/ContentDocuments/ISHLT_Call4Abstracts_2017.pdf
To Infinity and Beyond: What Does Destination Therapy Mean to Me?

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Destination therapy is a permanent, advanced heart failure therapy that involves a surgically implanted mechanical heart pump used to support a patient's failing left heart ventricle. This therapy is intended for patients who are not candidates for heart transplantation.

For a patient, this means that he or she will live the remainder of their life mechanically supported with a left ventricular assist device (LVAD), a mechanical therapy to manage their end-stage heart failure.

Living with the LVAD becomes a way of life for the patient and caregiver, usually a family member. They both learn to manage the equipment, such as batteries and the controller, and at-home procedures, such as dressing changes, that are part of their everyday life.

Most patients choose LVAD therapy to improve their quality of life and to experience fewer heart failure symptoms, allowing them to spend more time with their family and loved ones. Living with an LVAD is not without risk, and often complications can occur while on the mechanical support that can reduce the patient's quality of life and can cause time spent in the hospital. Patients and their caregivers are educated about the potential risks and complications prior to the surgery to ensure they are fully informed about life on the LVAD and the dedicated roles and responsibilities that must be undertaken by the caregiver.

It is important that the LVAD team carefully discusses with the patient what level of quality of life is acceptable, should complications occur -- a decision that is different for each patient and caregiver to consider.

Gustav Stiehl is an almost nine-year veteran on the HeartMate II that was implanted in him during a clinical trial in January 2008. He recently agreed to candidly discuss what it is like to live his daily life with an LVAD. When asked about his first thoughts when told about the prospect of receiving an LVAD to manage his end-stage heart failure, he said, "I don't remember too much about that time. I was so sick and in the ICU. But I do remember that my wife and I had a discussion about how the LVAD would give me the chance of a few more years in this world." Stiehl's wife recalls being told that her husband could go into hospice, or could receive an LVAD that could give him three-to-five more years of life, with hope for an improved quality of life.

Stiehl also went on to note that because he is only given so much time on this earth, that if his life could be extended for only one year, it was worth it.
He admits that the initial recovery after receiving his LVAD was very difficult. "I was so debilitated when the initial recovery was slow and challenging, but I kept telling myself that it was better than the alternative."

The LVAD, attests Stiehl, has provided him the ability to continue the activities he loves, such as playing golf, traveling around the world and singing in a choir.

The most important thing of all for Stiehl is spending time with his family and friends.

Stiehl has met with and advised many patients over the years who were considering an LVAD. He tells them that the choice is difficult, and that they would have to make some significant lifestyle changes. But to Stiehl, those changes are minor, and he says that he functions pretty normally.

Life on the LVAD has not been without some complications for Stiehl, including a stroke that happened during his sixth year on the device. Also, he required a pump exchange for a thrombus that he says hasn't slowed him down "as much as growing nine years older has."

When asked what advice he has for those considering an LVAD, he counsels, "Get the LVAD early, before you get too sick. And always keep a positive attitude and live every day as fully as possible."

He says it sincerely when he considers his nearly nine years on his mechanical device: "I am blessed to be living 3,180 more days longer -- and counting -- than I would have without my LVAD."

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Showing Up

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"Sometimes the bravest and most important thing you can do is just show up.” – Brene Brown

In thinking about this month’s edition, I must confess that I had a bit of writer’s block and even thought about skipping out this time around. Given the fact that I have moved to a new city, started at a new institution, crossed the line into the world of adult healthcare and stepped into a manager role for the first time this summer, change might have been an easy target. My inspirational muse however was having none of it. As a huge fan of Brene Brown’s work, I have read this quote about showing up more than once. When I came across it again on Friday, I took it as the universe giving me a nudge.

When interviewing people for any position in transplant, I always tell them this work is the rollercoaster ride of a lifetime and there is never a dull moment in transplant. Most of us could work around the clock and still never check off all of the boxes on our “to do” lists or ever completely tackle that perpetual someday pile on the corner of our desk. As a coordinator, my biggest end of day struggle always came back to, did I spend enough time in the right places? What if I spent a few more minutes with the patient and family in clinic who were struggling with waitlist fatigue or the newly transplanted teenager struggling with chest tube anxiety? Did I give enough time to the mother of a new referral on the phone whose world was turned upside down with the news that she would have to pick up and relocate her family’s life for an indeterminate amount of time to undergo the rollercoaster of transplant? My end of day struggle has shifted with my new role, but I still have that same nagging feeling. The difference now is that instead of worrying about my patients and families, I worry about my team. Did I make sure and check in everyone today? Do they feel supported and valued? Are they getting out of here at a decent time and did they get enough sleep while they were on call? How can I help them from falling into some of those all too familiar traps I struggled with?

What I try to always remember, and now stress to my team, is that sometimes the bravest and most important thing you really can do is to show up each and every day. No news to anyone reading this, but transplant is not for the faint of heart. It demands an unyielding level of time, brain space, energy and emotional reserve to do this work day in and day out. The reality is sometimes all we can do is show up. There’s no guide book for what to say to a parent of a dying child, a teenager in rejection or a staff member losing the war to finding balance in their life. I don’t always have sage advice and sometimes have no idea what to say at all, but I do my hardest to show up and be present. Some days it feels like I spend my entire day in meetings, putting out fires and getting nothing accomplished, but I just keep hitting the reset button and showing up.
So here’s my two cents advice portion of this article. When you have no idea where to start or what to do, start with showing up. You can’t connect with patients and families if you don’t show up and you’ll never fully appreciate all the transplant roller coaster ride has to offer if you don’t learn to connect.

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What Were You Doing in 1996?

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It was the 1990’s. Beanie Babies, Power Rangers, Tickle Me Elmo, and the first round of Pokémon were the rage! Do you remember when Starbucks started making Frappuccinos, PlayStation was released and eBay made its debut?

Recently, when we informally surveyed colleagues regarding what they did in 1996, most seemed to need to pause and think carefully to remember. Many referred to school, medical fellowships or described just getting into childhood mischief. Life is certainly unpredictable. Sometimes it includes unexpected detours that disrupt our best laid plans.

Ah yes, the 1990’s...ventricular assist devices were continuing to move beyond research and becoming more of a reality. 14 year old Michael had been diagnosed with dilated cardiomyopathy as a young child but his parents had kept him stable with regular visits to his cardiologist at Children’s Hospital Los Angeles (CHLA). However, by 1995, things began to change. He began to feel more tired, short of breath with activities, and loss of appetite. When oral heart failure medications were maximized, and he still showed signs of getting worse, he was admitted to the CTICU to receive intravenous inotropes and was listed for heart transplantation.

As the weeks passed he began to decline. CHLA’s affiliated USC Cardiothoracic Surgery adult program (shared surgical talent) had already been implanting ventricular assist devices (VADs) but the VADs available/in use were precisely that….for adults. The HeartMate LVAD (released by the FDA 1994) was considered for him because the 14 year old male was large enough to likely benefit from its support. We at CHLA worked with our adult hospital team to implant the device by January 1996.

The 63 days awaiting transplant weren’t all “bad”. After all, he was able to walk a bit and even go to the garden, with one of his many trustworthy nurses, to see some scenery other than the inside of the CTICU. It was actually during an excursion to the garden that Michael noticed some blood from his driveline site. He was taken to the OR urgently for a repair at the aortic site. Like the true champion, Michael recovered.

His loyal family visited as much as possible all the while working to keep their home and family intact. His mother became well known to the guest relations personnel and nursing staff. The strongly quiet, well-mannered teenager was amazing to us all.
"OMG! ", we exclaimed ...but without text capability back then. A donor call came in and Michael got his heart transplant in March of 1996. Recovery: not an easy task by any means, especially after having that chest open again, but nevertheless, he did it!

Always compliant with the medical plan, he kept his clinic appointments to see his cardiologists and took his immunosuppression as ordered...but who is it that ALL transplant kids really want to see again? The surgeon, of course! So, on a clinic visit, Michael and I figured we could catch the surgeon for a quick greeting. No cameras on our mobile phone yet in the 90’s, but we just happened to have a camera with us and...Gotcha!

One of the first heart transplant patients in our institution to “transition” to an adult center, Michael was well into his twenties...not that unusual back then...when he transferred to the age-appropriate facility and team. Although it is never possible to accurately depict in writing, the extreme challenges our transplant patients and their families have faced, some do stand out in our memories as exemplary STARS for the way they have met and overcome life’s obstacles.

Michael has been busy. A security guard and a softball coach for many years, he more recently has been pursuing a real estate business with his sister. He contacted us a few months ago and gave an impressive talk on his experience as a transplant patient on behalf of Donor Awareness Day. His old cardiologist and his old coordinator (yes, we are still here) attended. His surgeon was busy in the Operating Room...however, we managed to snap a photo of the two via current technology (iPhone) as the surgeon went between cases. By the way, Happy 20th Transplant Anniversary Michael: Way To Go, Coach!!!!!

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A Brief Update from the Pathology Council

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The Pathology Council has been busy in 2016. As in recent years, antibody-mediated rejection (AMR) has remained a strong focus of our Council’s efforts as we seek to better understand the phenomenon of AMR and the nature of “mixed rejection”, to refine our diagnostic criteria and relevant biomarkers for such, and to disseminate this information to pathologists. To this end, the Council put together several collaborative research groups this year during the last Annual Meeting to facilitate multi-center studies on these topics, and our members continue to expand available online resources for transplant pathology.

Pathology Council Initiatives

First, the Council has established a working group to investigate inflammatory burden in cardiac AMR. Gerry Berry together with Ornella Leone, Annalisa Angelini, Patrick Bruneval, and Jean Paul Duong Van Huyen are discussing a protocol, and will invite other centers to participate. Second, the Council has agreed to look at potential markers of chronic rejection in our biopsies, learning from experiences gained in other solid organ transplants. A small group has been put together to discuss a possible protocol, with the intent of setting up another collaborative multi-institutional study. This group includes Martin Goddard, Elizabeth Hammond, Bobby Padera, and Annalisa Angelini. In addition, other research and educational initiatives have also been proposed, and although these are in their infancy, we can certainly expect more to come. Stay tuned for updates and invitations to join these collaborative efforts.

Members of the Pathology Council also continue to be engaged in concerted efforts to develop better online tools for transplant pathology. In recent years, members of our Council have developed and are continually updating an online tutorial on cardiac ACR and AMR for pathologists, including online quiz components, in partnership with the Society for Cardiovascular Pathology and Association for European Cardiovascular Pathology (http://scvp.net/acr/index.html). This online tutorial continues to be well received, but any suggestions for improvement that you might have would be welcomed.

Not to be outdone, pulmonary pathologists have also begun to develop online tools to aid pathologists in interpretation of lung transplant biopsies. This year, our European colleagues led by Fiorella Calabrese have developed a tutorial website for pulmonary AMR, hosted by the European Society of Pathology (http://lungtransplant.dctv.unipd.it/amr/index.php). This website is a work in progress, and eventually will include all aspects of lung transplant pathology. If you encounter good examples of diagnostic grades of rejection or other entities in lung transplant pathology that could be included in this online resource, please contact Fiorella Calabrese at fiorella.calabresse@unipd.it.
One of the Pathology Council’s ongoing challenges remains dissemination of knowledge about the practical application of rejection criteria to practicing pathologists on the “front lines,” many of whom are not ISHLT members and most of whom evaluate these specimens as a small component of their broader duties in surgical pathology. The ISHLT Board is keen that we continue to engage with our pathology colleagues, including those who are non-members. We urge our Council members to continue reaching out to pathologists in other centers who practice transplant pathology, to keep them informed and to encourage them to consider joining us. Pathology remains an under-represented specialty in the ISHLT and we would all benefit from adding more members. There is considerable expertise in transplant pathology out there among non-members that remains untapped! Please spread the word.

**2017 Annual Meeting & Scientific Sessions in San Diego, CA.**

Perhaps the most important news related to the upcoming Annual Meeting in 2017 for busy pathologists is a change in the format of the Annual Meeting. Beginning with this next meeting, program content relevant to the Pathology Council will be clustered into a single day (Friday, April 7), instead of being distributed throughout the entire meeting over several days. Hopefully this concentration of program content will shorten the time away from our practices and allow more of our members to attend. Please spread the news to your pathology colleagues, especially the ones who may have been interested in the past but couldn’t attend due to time constraints. In any case, you won’t want to miss our exciting pathology-oriented sessions in San Diego next spring.

For more details about the upcoming Annual Meeting, please keep your eyes on the ISHLT website at [http://www.ishlt.org/meetings/annualMeeting.asp](http://www.ishlt.org/meetings/annualMeeting.asp). The preliminary Scientific Program should be released very soon.

See you all in San Diego!

Disclosure statement: The author has no conflicts of interest to disclose.
CALL FOR ISHLT 2018 JOINT SYMPOSIUM APPLICATIONS

Interested in collaborating with a related professional Society on a Symposium for the 2018 ISHLT Annual Meeting? See below for details and deadlines. Note: all ideas for joint symposia must be vetted through the Education Workforce Leader of a relevant ISHLT Scientific Council.

DEADLINE FOR SUBMISSION OF APPLICATIONS
TO ORGANIZE A JOINT SYMPOSIUM AT ISHLT 2018:
FEBRUARY 1, 2017

APPLICATION DECISION:
MARCH 31, 2017

DEADLINE FOR SUBMISSION OF PROPOSED
JOINT SYMPOSIUM CONTENT:
JUNE 1, 2017

SYMPOSIUM SELECTION NOTIFICATION:
JULY 2017

PROCESS:

- **February 1**: Deadline for submission of applications to organize a joint symposium for ISHLT 2018. All applications must be submitted by a Council Officer or Education Workforce Leader of an ISHLT Scientific Council.
- **March 15**: Submitting Councils will be notified regarding selection. For approved applications, work may begin to jointly develop session content in accordance with ISHLT policies.
- **June 1**: Deadline for submission of proposals for joint symposium content
- **July 2017**: Symposium proposals scheduled for inclusion in the 2018 Annual Meeting

IMPORTANT NOTE:
Please DO NOT begin developing content for a joint symposium until you have received notification in April that your application has been approved.
What are you looking for? At times, it best to let others speak. Reread this must read issue.

Happy Halloween!

Disclosure statement: The author has no conflicts of interest to disclose.