

# Beauty and the Beast

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### **Introduction**

I am pleased and honored to have the chance to speak with everyone today. And I admit I am a little nervous, as I want to try something new. I am using visuals provided by my wife Erica to try and add an emotive quality to what I have to say. These paintings are the first from her new career as a painter so I thought that it was appropriate for this meeting which is organized by our newest members.

First, I want to say that the last 8 months as President of ASTS have been an absolutely incredible experience. It's been a terrific opportunity and honor. To say I've learned a lot from colleagues and ASTS staff would be an understatement. While very busy and sometimes challenging, mostly it has been a joy having the bully pulpit and representing this great Society in discussions and conversations with colleagues, thought leaders, policy makers, regulators, and allied organizations such as AST, UNOS, Organize, and OPO's and Industry. I've been given the opportunity to work with many people I already knew well and also many new, committed, smart and remarkable individuals. It really gives me faith in the future of transplant.

And the overarching feeling this experience has given me is pride. Pride in what we do, pride in my colleagues, and pride in where we want to go. A pride, not turned inward rather one that engenders inspiration; inspiration to do even better.

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### Symposium

So for any organization like ours, the million-dollar question is always – as a field and as a community, where are we and where do we want to go? The theme of the last few days says much of it – “Limited Supply, Increasing Demand: Expanding Organ Donation.” I know – it’s the age-old question in transplantation. But it remains at the epicenter of the many challenges we face as transplant surgeons. We’re not exactly like our brethren in orthopedic surgery who buy their supplies from manufacturers and can just access them off the shelf in the OR. Just think of this; how crippling would be the unmet burden of osteoarthritis if orthopedic surgeons had to rely on vascularized hip or knee allografts for total joint replacement. So resource scarcity is our special burden as transplant specialists. It is truly the issue that differentiates transplantation from all other medical specialties and is the issue I focused on for both the theme for the Winter Symposium as well as the theme for my Presidency.

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While I was reflecting on what I might talk about today, I tried to reconstruct my thoughts and feelings that lead me to focus on this theme. Well, I guess my thinking went something like this...much like my comments about the visuals, this is the Winter Symposium, the ASTS's signature meeting. It is truly the vision and work of the Vanguard Committee, a committee that was born during the Presidency of Ron Busuttil to enfranchise and harness the energy and enthusiasm of our newest and most passionate young members. And working with this wonderful group made me think back in time to a place very early in my career when I was full of energy, enthusiasm and the desire to be innovative and look for a field in surgery that would allow my imagination to soar. And today, I have 2 stories to tell you; I call them collectively, "Beauty and the Beast."

### **Story 1 - Beauty**

The first story that I call "Beauty" (**Slide 4**) takes place relatively early in my residency. During my second year, I was lucky enough to do a 2-month rotation on the kidney transplant service with Lewis Burrows. Lew Burrows, who unfortunately passed away just a few months ago, loved the art and magic of transplantation and imbued a great number of ASTS members with that same love; Avi Shaked, Lew Teperman, Ron Shapiro, Linda Sher and me, to name just a few. At the end of that rotation, Lew invited me to spend my entire 3<sup>rd</sup> year of residency working on the

Transplant service in both a clinical and bench-top research capacity; it was an incredible opportunity. The combination of clinical and bench work was the epitome of translational education and clinched my interest and passion in transplant.

My bench research was investigating the combination of donor specific blood transfusions and cyclosporin in the rat heart transplant model. My problem was mastering the heterotopic heart transplant; I think I killed most of the rats in NY! The problem was that every time I thought I was getting the hang of it, my beeper went off with an urgent clinical issue that took precedence; it was really challenging. I had just met Erica a few months before and we were living together. So I had the bright idea of a really cool date; we could both go to the lab one evening. There would be peace and quiet; I might get the “interruption free zone” I needed and she could see what I was doing or more likely just read her book. What a cool guy I was... anyway she agreed!

I got through the procedure and got ready to release the clamps with a dread based on my past 100 failures. But I took the clamps off, there was no bleeding and the heart started to beat for the first time. I let out a shriek of joy and called Erica in to see. She was amazed. It was a magical and exhilarating moment that we shared and fully enjoyed; I think her support

that night gave us both an enduring passion for the field and the mutual commitment to endure through the many hurdles that might come in the years ahead. And I discovered that with commitment and persistence, I could perform these heart transplants with a high rate of success that ultimately allowed for a publication in *Transplantation*. More importantly, I think I found my career, and my wife that night!

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But it wasn't a linear path. I became enamored of vascular surgery, did a fellowship in vascular and detoured into the full time vascular surgery practice at Mount Sinai. But 15 months later, I was offered the opportunity to learn liver transplantation and start a program there. So off I went to Pittsburgh to learn from our Founding President, Tom Starzl, with my daughter Jessica and with Erica who was pregnant with Samantha in tow... what craziness! But I met great people, worked like crazy, learned a ton and fell I love again with transplant, and this time it stuck. But as much as I did learn about the art and science of liver transplantation, I was still ill prepared for the politics of transplant in NY and the pressures and complex dynamics of heading up a new high profile institutional endeavor. And mistakes I made...and as uplifting as my first story was... this next one was not.

### Story 2 – The Beast

So now for the “Beast” (**Slide 6**)...After my year in Pittsburgh in 1986, I returned to Sinai to build and train a team and start-up the liver program only to find enumerable state and local political hurdles. But after 18 long months, we got the necessary approvals and our young team was rarrin’ to go!

The first case was a resounding success; lots of high fives! The second case, not so good; PNF but followed by successful re-transplant. There was an audible institutional gasp! And then our 3<sup>rd</sup> case, a beautiful 18 y/o girl with severe autoimmune hepatitis. Another bad graft! High enzymes, coagulopathy but this time a positive cross-match. Having seen one case of hyperacute rejection in Pittsburgh, and feeling rather desperate not to re-transplant 2 of our first 3 cases, I decided on a course of immune therapy. I put on my rose colored glasses and tried to convince myself daily that things were improving...until she crashed, was resuscitated, re-transplanted too late, and died a week later of sepsis.

And in that moment I saw the terrible conflict I was confronting; my physician’s duty to the patient and a fiduciary duty to the institution to have a program with great results that wasn’t wasting organs. But the truth was I hadn’t had the fortitude to do the courageous thing of putting my patient’s best interest first, re-transplanting her early and accepting another early graft loss; I had tried to satisfy both interests and failed miserably. It was

crushing and I found myself in a back stairway crying my eyes out and re-thinking everything. I was furious with myself as well as scared and feeling quite alone. But stairwells get used by others and a senior surgeon came upon me and kindly spent some time listening. I actually don't remember the substance of the conversation but I do remember the message; just collect my thoughts, re-focus and keep moving forward, and always try to put patients first.

And 30 years later, this “Beast” of transplantation created by our many masters continues to haunt everything we do. So I ask you today, how can we stay true to our collective vision of “Saving and improving lives with transplantation” and do the best for all of our patients in a scarce resource, highly regulated “battle-field triage” environment? How do we transform the Beast into the handsome Prince that Beauty eventually marries?

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#### **Vision - Mission - Strategic Plan**

Well there are no simple answers but I believe the root cause that differentiates us but also creates so many of our problems, regulations and tribulations is the organ scarcity. So what can we do...well the way I like to approach the many issues that present themselves to the Society is to use our ASTS Strategic Plan as a kind of organizational GPS. Some issues may not be relevant to our strategy and deserve minimal attention while many focus on one or two of the sectors of the Plan; those sectors being

Advocacy, Research, Training and Professional Development, and Optimal Patient Care.

But, to address the issue of organ scarcity in a transformative fashion will take a highly coordinated approach that encompasses all four quadrants of the Strategic plan and requires real ASTS Societal leadership to coalesce and guide the many other stakeholders in the global Transplant Community.

So, I dream of practicing transplant surgery in a non-scarce resource environment; because “The Beast” survives and thrives when we must deal with the complex pressures and burdens that scarce resources impart. This dream is no small goal; it is what we call a BHAG, A Big Hairy Audacious Goal. A goal that, if achieved, has the potential to change the way we think and practice transplantation. The ASTS first learned of the expression BHAG from Mike Abecassis and his readings of Jim Collins’ book, *Built to Last*. It’s a great book and something I will get back to later. This BHAG started as an aspirational goal and over the past six months has taken on a life of its own. It now has real tangible aspects that are part of our coordinated approach and encompass all 4 sectors of our Strategic Plan. Let me discuss a few of the many initiatives that will allow us to be successful.

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Let’s start with Optimal Patient Care sector and the formation of the PROACTOR task force. PROACTOR means (**PRO**viding better **AC**cess To **OR**gans). In June, I asked Dorry Segev to lead this new Task Force and

organize a team of our members to review issues in organ donation and access. I asked him to survey the landscape to understand the myriad of initiatives – big and small – already underway in our community, create a Society White paper that will then inform a 5-year strategic plan on this issue. While many people and various groups are already working in this space, PROACTOR will advise us how the ASTS can make the biggest impact and who we should partner with to build a social network that changes organ donation into something “cool,” like the folks at ORGANIZE like to say. It will also guide and advise us where we should allocate our resources going forward. The work is well underway.

The NLDAC (National Living Donor Assistance Center) is an important piece of our Optimal Patient Care strategy to remove disincentives to living donor donation. By helping donors avoid financial disincentives, we are “doing the right thing” for them and those on transplant waiting lists.

As we stated in our in congressional testimony this past Spring, it is really exciting to be able to say that the NLDAC program has helped facilitate organ transplantation for over 2,500 recipients since it began. It has not only saved lives, but has also saved the Medicare program over \$60 million in dialysis service. And most importantly, almost 75% of donors who have participated in NLDAC say they wouldn’t have been able to donate without it. That is BIG!

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What have we done in terms of Advocacy ... As I toured the country this Fall, attending 5 separate UNOS Regional Meetings for informal discussions with our Members and guests from UNOS, the message was loud and clear! The sense of PSR and CMS induced risk-aversion in candidate and organ selection was on the top of everyone's mind. It is clear that the outcomes of almost all programs have improved and are approaching an asymptotic point where flagging is occurring for purely statistical, but not clinically relevant differences; especially when viewed in the context and contrast of the outcomes for those who never get an organ. We all know what happens with flagging and the potential for SIA's. Risk aversion flourishes, needy and deserving albeit more risky patients without "good risk adjusters" go unlisted and 4000 organs that are procured get discarded. Program preservation begins to overtake and supersede patient care.

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I am proud to say that we have been extremely well represented at UNOS by Mitch Henry. At the Direction of Council, Mitch was asked to argue for and create a political action that would set in motion seismic change in the way the PSR's are calculated and reported and would eliminate flagging for purely statistical reasons and result in a substantial diminution in flagged programs.

Through careful planning with his organizing group and intense diplomatic discussions with the UNOS Board, Mitch's resolution was passed. It instructs the MPSC to create a group of quality metrics that are able to identify programs with only clinically relevant quality issues, and to create this plan in the next 6 months! These changes have the potential to create a climate that incentivizes the type of calculated risk taking that promotes organ donation and utilization and improves overall patient care. We must keep the pedal to the metal so as not to lose momentum! And I know Mitch will keep this moving.

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Within Research, the IOM study on organ donor intervention serves as a tangible example of ASTS tenacity. Based on the tireless efforts of Sandy Feng and Peter Abt, the IOM was asked to evaluate this issue for a potential study. As you know, past IOM studies have carried great weight and changed our field. I was delighted to be a part of a July meeting at the National Academies of Sciences. At the conclusion of the deliberations, the IOM agreed that this issue merited an IOM study. In a move of leadership, ASTS was the **first** organization to publicly announce a funding commitment to the study. Since then, at least six additional groups have announced support including the Arnold Foundation with a very generous contribution as well as AOPO, AASLD, AST, and NIH institutes NIAID and NIDDK. I look forward to the deliberations of the IOM and am confident that the recommendations that emerge will provide an

organizational framework and roadmap that will catalyze more coordinated research that will lead to improved quality and quantity of deceased donor organs; there is light at the end of the tunnel!

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When it comes to the Training and Professional Development arena, meetings such as the Fellows' Symposium, ATC, the new lap donor course scheduled for March 2016, and the Winter Symposium exemplify how ASTS uses training and education to support the BHAG.

I am very excited to remind you that you are in for a compelling session this afternoon with our 6 former Surgeons General. Let me describe the path that led to the development of this session. When Peter Stock was preparing for his Presidential Address here last year, he asked past and present leaders what we need to do as a Society. One of the most impassioned responses came from Former President, Oscar Salvatierra. He suggested that we have to have a national campaign to increase organ donation, a campaign with the imprimatur of the Surgeon's General office, along the lines of the campaign to reduce smoking. So when we were in DC for the IOM meeting, we had dinner the night before with a unique group of colleagues. Dr. Ken Moritsugu, a former Surgeon General and his lovely wife Lisa Kory, joined Greg Segal from Organize, John Creel and Darmesh Patel from Novartis, Peter Abt, Doug Hanto and Kim Gifford and myself. As we talked about the challenges we face, we kept coming back to the main issue –increasing our

patients' access to the organs they need to survive. Were there lessons to be learned from other specialties? How have the Surgeons General tackled other big national health issues? From this conversation, Ken graciously offered to invite his former Surgeon General colleagues (I think it is an exclusive club!) to discuss and brainstorm this issue with us. Incredibly, they all accepted! I am sure what will start today will raise societal awareness of this growing public health issue and strengthen our resolve to galvanize the community around our goal and our vision to save and improve more lives through transplantation.

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#### Altruism

So those are many of the specific initiatives that make up this evolving strategy. But what do we use to hold this strategic initiative together; what is the glue that keeps us focused and moving in the right direction? My answer to the question is our Core Values that we live and work with. And I wanted to focus on a Core Value central to transplantation: that is altruism. It is interesting to consider that Altruism is the requisite catalyst for every single transplant we do. That *single* fact creates a stark contrast to almost all other transactions in our media driven world where egoism, the direct opposite of altruism, seems to Trump all; sorry for the pun!

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Most of the transplant literature regarding altruism appropriately revolves around donors. Deceased donors, donor families and living donors alike, selflessly volunteer to make life-giving gifts to others, known or unknown, with no real identifiable benefit except the personal satisfaction of helping another. It is truly remarkable. But I want to challenge all of us to look at altruism in a much broader and simplistic way than most bioethicists and medical anthropologists commonly do.

If we are to be successful, donor altruism is first and foremost, and must be recognized, respected and supported. But I would argue that we need to promote the value of altruism in transplantation in a way that extends beyond purely the donors. It needs to be a Core Value that guides how we treat one another, both within the ASTS and throughout the Transplant Community. In order to truly honor our donors we need to recognize that altruism in transplantation must be promoted and incorporated in the work we do every day and we must set an example for the providers, administrators, policy makers, regulators and the media.

So how can we do that? Well first of all, there is a strong tendency for “idea ownership” in this donation space. I think we all need to realize that no individual or group in the transplant community owns the best or the only idea. We need to network and collectively build on the many themes and ideas out there and focus on the best. And in that vein, the members of the

PROACTOR task force have special ribbons and are hoping to learn more about your center-specific initiatives that have been successful. As an example, Dorry's recent characterization of a "Donor Champion" and the benefits of that strategy in helping better identify living donors shows how smart new ideas can have big payoffs. Please reach out to the PROACTOR's and share the ideas you have and are working on at home!

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There are many other simple and generous to express altruism. For example, I was discussing this concept with Carlos Esquivel and he suggested that we better help each other with donor procurements to save each other time, effort and cost as well as avoid the well-known risk of air charters. Figure out more liberal ways to split livers that makes grafts easier and better to share for both yours' and your colleagues' patients. Work together collaboratively on scientific projects, social networks, advocacy and training programs designed to improve the field. Be generous with your colleagues; listen carefully to their needs, their trials and tribulations and be giving of your wisdom and knowledge where and when it is needed.

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Then our call to action will not go unheeded. When we ask our partners in the Insurance world to work with us to ensure that there are truly no financial disincentives to living donation, they will indeed work with us. When we go to the regulators to insist that together we do everything to

maximize both the quantity and quality of transplantation for our patients, we will be heard. And no matter how far we eventually go with our “Arc of Change” as beautifully described by Alan Langnas and Dan Solomon in last January’s AJT, altruism will remain the cornerstone of donation and transplantation, and we must incorporate that value into our professional lives as never before; we must walk the walk as well as talk the talk.

### Slide 17 (Lucy)

You know, in many denominations of religious and philosophical writings, the words “altruism” and “love” are used synonymously. And to segue back to our little fairy tale, the only thing the Beast had to learn in order to be transformed back to a Prince was how to love.

### Slide 18

But can we explore pastures beyond pure altruism as suggested in the Arc of Change? What will it take to utilize positive incentives once all disincentives to donation are removed? Well to try and answer that question, let me segue from Beauty and the Beast—altruism and love—back to Jim Collins’ book on the most successful companies. What do those successful companies have in common? I would tell you the overarching theme is the importance of Core Values. As important as a good business plan is to a company, the great and enduring companies have both a good plan and a clearly enunciated set of Core Values that guide how they work on the plan every day. I believe that is what will make further exploration of

the Arc of Change possible. We need as a Society a well thought out and clearly enunciated set of Core Values that guide us. Make no mistake about it, when the time comes to explore incentives beyond pure altruism there will be harsh and loud critics, some with absolute religious zeal. We cannot be defensive. We must be prepared and armed with our own set of Core values to gain the ethical high ground. So I tell you today that I will make the discussion and promulgation of ASTS Core Values a priority for the remainder of my presidency, for they will be the fuel, the glue and the armor needed to make our Strategic Plan successful. The sad fact is that we live in a metrics driven world. But as we have learned in this symposium, a metrics driven world can lead to misaligned incentives, unanticipated negative consequences and gaming of the system. I submit to you that it is quite difficult to game a Core Value based system because the core value create an internal gyroscope and self-righting mechanism that can both protect us and keep us on track.

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So collectively, we can effect change. The ASTS is a big team whose members are fully committed to improving the field. We're trying to get it right by focusing on our Strategic Plan. And it is only through your ideas, dedication, passion, expertise and hard work that we can make real change.

We all have to be involved. When you get home please think about how you might enhance your ASTS involvement and how you can be more involved

and let me know. Because when I look out from here, I see a vibrant and eager group looking to help and looking to lead, and when we work together we can really effectuate positive change for our patients and donors who always continue to inspire.

And this is why today I feel such pride – pride in our field and pride in you, our Members and friends. And so today, I am more optimistic in our future than ever before.

And through our adherence to our Strategic Plans and Core values, our work will be transformative and bring new promise to our patients and to the field.

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### **Summary and Closing**

In closing I want to recognize my wife Erica and my daughters Jessica, Samantha and Emily. Thank you for your continuing encouragement through all the stories good and bad, for your ideas for this talk, and for the beautiful paintings! It's great to have all of you here!

I also must recognize my great Clinic team in both Cleveland and Weston whose loyalty, talent and passion are unsurpassed. Thank you for working extra hard this year to allow me the time to carry out my duties as President. It is an honor and privilege to work with you.

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And I am here to tell you that we have a great leadership group in both the Executive Committee and Council who provide wisdom and experience to all our deliberations; I want to thank each and every one of you for your advice, counsel and support. And thank you to our wonderful ASTS Staff who are a terrific and empowered group who provide incredible support for the entire spectrum of what we do. And they are led and empowered by our Executive Director, the truly incredible Kim Gifford, who thinks her job is to “make me look good”! Thank you Kim; you all need to know that Kim is worth her weight in gold, but since we’re a non-profit, we only pay her in tin.

I hope you have enjoyed your time here in South Beach, and please enjoy the rest of the conference and I am very excited for the upcoming Surgeon General panel. Thank you for your attention and thank you for the privilege of the floor.