



Lifelines

October 2013



Transplant Recipients International Organization, Inc.

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The Transplant Community and TRIO Have Lost a Dear Friend

Ana Stenzel passed away Sunday morning, September 22, at her Redwood City, CA, home surrounded by her family and husband Trent. She was a passionate advocate for organ donation. “She led a defiant fight until the end against gastrointestinal cancer, a result of the cystic fibrosis that led to lung transplants for her and her twin sister Isabel,” said San Francisco Bay Area TRIO Chapter President Monet Thomson.

Stenzel was energetic and prominent in the fight against cystic fibrosis and behind organ transplantation. She and her twin sister, Isabel Stenzel Byrnes, vaulted to prominence in the CF and transplant community with the publication of their book “The Power of Two, A Twin Triumph Over Cystic Fibrosis” in 2007 and in 2011 a highly acclaimed motion picture.

Her sister wrote, “Ana was the power behind the power of two; her feistiness, dark humor, angst, bossy leadership, tireless energy and fierce willpower have been a driving force for me and all that we have accomplished together.” She added that her sister would be cremated with a photo of James Dorn, her first donor.

“Ana’s passing leaves an immense hole in the San Francisco Bay Area TRIO Chapter,” said Thomson. “Even while struggling with her illness, she re-wrote and designed the chapter’s new brochure, organized the chapter’s participation in a giant Fourth of July parade, designed new t-shirts and banners, served on the board, lined up speakers and drove the Team NorCal/SF Bay TRIO agreement for the Transplant Games, in which she was a passionate participant.

Noted donor parent, author and speaker, Reg Green, wrote to Isabel, “I met Ana and you because you had turned your personal history into a universal story. Now the two of you have transformed the universality of death into an unforgettable personal event. I cannot remember ever being moved so much by any other

eulogy. Perhaps I shouldn’t be surprised. Of the thousands of organ recipients I have met, no one has the combined insight, courage, and beauty of living as memorably as Ana and you.”

Anabel Mariko Stenzel was born in southern California in 1972 to a German father and Japanese mother, Reiner Ludwing and Hatsuko Arima Stenzel. Stenzel’s ties to her parents’ homelands ran deep, particularly Japan, where she often traveled with her sister. She was highly cognizant of the special problems the idea of organ transplant posed in Japan.

The twins each received their lung transplants (Ana two, Isa one) at Stanford University, where they also did their undergraduate studies. Ana subsequently received her MS in Genetic Counseling at UC-Berkeley and then worked as a perinatal genetic counselor.

Isabel noted her sister’s favorite quote from Hunter Thompson, saying it so accurately described how she’d lived her life:

“Life should not be a journey to the grave with the intention of arriving safely in a pretty and well-preserved body, but rather to skid in broadside in a cloud of smoke, thoroughly used up, totally worn out, and loudly proclaiming ‘Wow, what a ride!’”

Below: Marty Maren, President of Maryland TRIO Chapter, with Isa and Ana, at the 2012 Transplant Games.



President's Message



"We do not defeat death with a transplant; rather, we gain an extension of life. So, the real question becomes: what are we going to do with the days, months and hopefully years of extended life? . . . same question even the non-transplanted face in their own lives."

-Quote from a heart recipient

Imagine my surprise to read that quote in a recent newspaper article from Fort Wayne, Indiana. You see, that "heart recipient" is me and that's a quote from my many presentations promoting organ donation, but I can't find anywhere that the writer of the article would have found it. Yes, I am trying to find out the answer to that question, just out of curiosity, no concern that somebody used my words, in fact, kind of honored they did. Its message is one of my strong beliefs and I hope that it inspires you as it does me to find a purpose in your life and to live life with passion in fulfilling that purpose.

The recent news that a good friend, Ana Stenzel, who has lived her whole life that way, had died of cancer, touched my heart deeply. It has equally affected the TRIO and world transplant community that she inspired with her spirit, outreach, book, movie and life, along with her surviving twin sister, Isa. Those famous Stenzel twins are the embodiment of that quote. With lung transplants that extended lives, they both have given back in such amazing ways, as Isa now continues to do. We all offer Isa and Ana's family our deepest sympathy.

In another testimony to that same message, TRIO is so pleased with the growth of our "volunteer staff" to five as we add yet two more members taking on special tasks in response to the newsletter "Want Ads". For years now, **Harriet Weiss** has worked every other week validating those 700+ web site links that provide a unique TRIO site resource for visitors. **Dennis Fogarty** calls TRIO members whose invalid email addresses bounce from our monthly E-News distribution, while **Nancy Brady** comes into the TRIO office to help with the mailing of TRIO's Transplant Presentation Library programs to chapters. Our two new volunteers will help with research for future outreach to OPOs and transplant centers, promoting TRIO into that broader community with offers of resources and patient support. They are answering that

question of how to make each day count in giving to others, both those who are recipients and those who are family and friends of the donor and transplant community, with service through TRIO that makes what we do every day possible. Thanks to each of them for their support! Want to join the staff? Just call!

In closing, we challenge you with that "**YBSW?**" phrase introduced in our recent E-News. That acronym stands for "**Yeah, but so what?**" and is meant to focus readers and our authors to translate the message into personal action and engagement. For this president's message, the opening quote is that challenge for each of us, to create our own answer to the question "**What are you/we going to do with the days, months and years of our extended lives?**" That applies equally for our non-transplanted readers. Take some quiet time to reflect deeply, then write down the goals you come up with, finally taking action to turn those dreams into goals that become your reality, a life fulfilled each day. TRIO strives to offer supporting opportunities for your life plan, especially as it involves giving back and helping others to overcome their own life challenges inspired by your example and support.

Sincerely,

Jim Gleason, President

TRIO Board of Directors

Heart Recipient: October 19, 1994

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Did you know?

There are **118,662** waiting list candidates!
Visit www.unos.org to see TODAY's number

UNOS Resources: 888-894-6361

TRIO's Quarterly Board of Directors Meeting

The TRIO Board of Directors held its quarterly meeting by teleconference on August 27, 2013, with Jim Gleason, Board President, presiding. In addition to the regular review of committee reports submitted in advance of the meeting, several other topics were discussed and decided.

Treasurer James Mateiko shared that TRIO continues to be financially challenged in this time of reduced grant and sponsorship funding that is reportedly impacting all non-profits during this economic recovery. The grant committee reported details of many grant applications submitted, but even those that have received funding in prior years are being denied so far this year. They reported on progress recruiting replacement advertising revenues and hope to have some new contracts shortly. All Board and TRIO members are urged to look within their own network of contacts for new opportunities for financial support and to report any suggestions to Sylvia Leach at TRIO headquarters.

Membership dues are becoming even more critical and everyone is urged to submit them to local chapters; or, in the case of members-at-large, to get 2013 dues (and 2014 if you wish to pay ahead) to the national office. With your continued support, and as long as we still carefully control expenses, TRIO's finances should remain in the black given current reserves.

It was decided that the previously approved 2014 Leadership and Educational Summit event will be held in the fall, with exact date and location to be finalized at our next meeting.

The Communications Committee reported that development of the totally re-designed TRIO website is looking good and continues under review with expectation of its formal launch at November's board meeting.

Under chapter development, Sylvia reported ongoing support for potential new chapters in Greenville, NC; Seattle, WA; Michigan, and outreach to the former TRIO Cascade chapter.

The Board scheduled its next meeting in Philadelphia at the Gift of Life Donor Program offices on Saturday, November 16, from 9 a.m. til 4 p.m. All board meetings are open and you are welcome to come and participate in person or by teleconference. Contact info@trioweb.org to register.

Leadership and Educational Summit 2014: It's Coming!

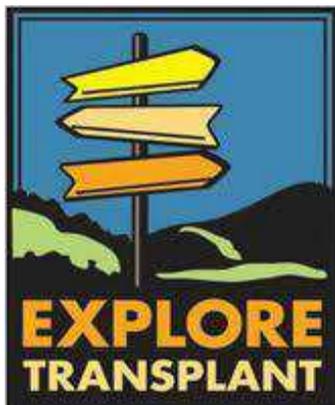
While the TRIO Board of Directors is yet to set the exact date and location for our new summit event, we can tell you that it will be in the fall, either mid-to-late September or in October of 2014. The two sites under serious consideration so far are San Francisco and Kansas City. In exploring these sites, the Board is trying to move from the east coast, where previous summits have been held, to an area of the country that would be more available to our mid-country and west coast membership. Those final details are on our November Board of Directors meeting agenda. So, stay tuned, but meanwhile, start saving your travel monies, even if you are planning to attend the Houston Transplant Games in July!

"YBSW?" What's involved in a 'summit event,' you may ask. Well, just go to the TRIOweb.org site and under "Communications/Resources" you can virtually sit-in on the workshops and presentations from previous summits. Certainly that is not just like 'being there' and participating in person, but you will get the idea. For some educational fun, check out the very popular 2012 panel discussion on "Sexual Intimacy Post-transplant." That session really engaged the audience and provided insight into the survey results many completed as a foundation for that session. The audience asked for a repeat of that topic with longer time to explore and share at future events, so that will definitely be on the agenda again in 2014! So, start saving your \$\$'s now for the trip ahead.

Have YOU Responded???

As part of a readership survey to help reduce unnecessary expenses by finding out who is actually reading *Lifelines* and possibly reduce this costly mailing only to those who wish to receive it, we ask that you e-mail info@trioweb.org or call 1-800-TRIO-386 with your name to confirm that you wish to continue receiving this hardcopy *Lifelines* or would opt for an e-mailed color version.

Note: *Lifelines* issues are archived on the TRIO website, and are available on our website in full color. Members responding with e-mail addresses will also receive an e-mail notice and link when each issue is posted.



Explore Transplant's Award Winning Education Program Improves Informed Decision Making

Kidney transplantation, especially a living donor kidney transplant, offers patients with kidney failure the possibility of a long and high quality life. Unfortunately, ESRD patients are not always fully aware of their transplant options and a limited number of kidney donors complicates the transplant process for many. That is where **Explore Transplant** comes in. After recognizing the general inconsistency of transplant information and educational materials available to dialysis patients and their potential living donors, Amy Waterman, PhD, and Associate Professor of Medicine at Washington University School of Medicine, created the **Explore Transplant (ET)** print and video educa-

tional program for potential kidney patients and living donors. Access to ET education programs has been shown to improve patients' transplant knowledge about the risks and benefits of transplantation, overcome racial disparities associated with transplants, and increase pursuit of a transplant.

Explore Transplant won the Quality-of-Care Award from NATCO -The Organization of Transplant Professionals, in 2009. Dr. Waterman and Christina Goalby, MSW, then created a non-profit organization, also called Explore Transplant, which provides two services: (1) training of dialysis providers to enhance their transplant knowledge and ability to educate dialysis patients using the award-winning ET educational program, and (2) dissemination of transplant education in both English and Spanish to dialysis patients and potential living donors.

To date, more than 2,500 dialysis providers nationwide have attended **Explore Transplant** trainings and are using the program to help their patients and their families make informed transplant and living donation decisions.

“YBSW?”: With the dialysis patient population being an underserved audience in need of education about kidney transplant as an alternative, see what you or your chapter can do to address that need in your local area; learn more about Explore Transplant at www.exploretransplant.org

Photo: Carmen Diaz, LCSW, delivers transplant education at chair-side with a hemodialysis patient interested in learning more about why patients get kidney transplants.



What's 'Kidney Buzz'?

With so much daily news updating on our own TRIOweb.org site, usually about five or six transplant stories added each day, it takes a lot to impress this TRIO webmaster. Recently I visited a new website for kidney patient stories and articles called 'Kidney Buzz' that was both strikingly attractive, educational and very active with new, timely content.

Launched by a recently graduated son, Cameron, inspired and supported by his father, a dialysis patient for more than 14 years, **KidneyBuzz.com** claims to be the nation's fastest growing and most reliable Chronic Kidney Disease (CKD) website. Its unique value comes with offering fresh news and information daily

that is useful and usable in real time to help members of the CKD community better manage and improve their lives.

“YBSW?”: Check out the site under “transplant” and then try these two recent articles: **“How Eddie Obtained his Kidney in Just 90 Minutes”** and **“Why This Kidney Donor Positively Responded to a Facebook Request From a Stranger in Only 90 Minutes.”**

Be sure to enjoy his daily inspirational quote. KidneyBuzz.com is quite an undertaking that is building a fast-growing following. And, while you're there, reach out using “Contact” and send a supporting note to that family team to keep it going.

TRIO Announces Six Scholarship Awards

The TRIO Scholarship Committee is pleased to announce that it has completed its work selecting the 2013 awardees of TRIO \$1,000 scholarships. As Chair of the committee, I would like to thank the following dedicated members: Susan Pincus, Steven Binder, Dorene Kray, Suzanne Himes and TRIO Managing Director, Sylvia Leach. These individuals spent many hours carefully reviewing and diligently analyzing more than 25 applications based on the criteria previously set.

This year, TRIO will be awarding six \$1,000 scholarships. These scholarships would not be possible without the generous contributions of the following groups and individuals. Four of the scholarships were made possible by TRIO chapters: Akron-Canton, Kansas City, Philadelphia, and San Francisco Bay. Contributions from three additional chapters, Nation's Capital Area, Maryland, and Greater Cleveland, along with a personal contribution from TRIO member Trudi Anderson made up a fifth scholarship. The funds for the sixth scholarship came from donations in memory of former TRIO Board of Directors members J.T. Rhodes and Alex Boyer, and from contributions from current Board members Harvey Mysel, Steve Okonek, Susan Pincus, and Elizabeth Rubin.

The TRIO Scholarship awardees come from four states: Hawaii, Texas, Oregon and California. Their names are: Victoria Bolin, Yolanda Domingo, Brandon Facon, Melanie Hansford, Shana Hansford, and Lisa Robinson. Each of them tells a very compelling story of his/her journey through transplantation, as recipient, sibling or spouse. We congratulate all six of them and look forward to hearing more from them in the coming years.

The 2014 TRIO scholarship application will be posted on the TRIO website, www.trioweb.org, in January of 2014.

- Elizabeth Rubin, Chair
TRIO Scholarship Committee

Volunteer Positions Available

Have you thought about just how valuable you are? TRIO can use your talent, whatever it might be! See Jim's message on page 2, about our current volunteers.

If you have an interest in getting involved with TRIO, let us know. Send your contact information to info@trioweb.org

Confused about Medicare and the New Health Insurance Marketplace?

How Will the Health Insurance Marketplace, Starting in 2014, Affect my Medicare Coverage?

The Health Insurance Marketplace is designed to help people who do not have any health insurance. If you have health insurance through Medicare, the Marketplace **will not** have any effect on your Medicare coverage.

Your Medicare benefits aren't changing. No matter how you get Medicare, whether through original Medicare or a Medicare Advantage Plan, you will still have the same benefits and security you have now, and you do not have to make any changes.

The Marketplace provides new health insurance options for many Americans. If you have family and friends who do not have health insurance, tell them to visit HealthCare.gov to learn more about their options.

Do I Need to Do Anything With Marketplace Plans During Medicare Open Enrollment (October 15 – December 7, 2013)?

Medicare's Open Enrollment is not part of the new Health Insurance Marketplace. It's against the law for someone who knows that you have Medicare to sell you a Marketplace Plan.

Medicare Open Enrollment (October 15 – December 7, 2013) is the time when all persons with Medicare are encouraged to review their current health and prescription drug coverages, including any changes in costs, coverage and benefits that will take effect next year. If you want to change your coverage for next year, this is the time to do it. If you're satisfied that your current coverage will continue to meet your needs for next year, you don't need to do anything. For more information on Medicare Open Enrollment, visit Medicare.gov or call 1-800-MEDICARE.

NOTE: The Health Insurance Marketplace Open Enrollment period (October 1, 2013 – March 31, 2014) overlaps with the Medicare Open Enrollment period (October 15 – December 7, 2013). Therefore, people with Medicare who are looking to make Medicare coverage changes should make sure that they are reviewing Medicare Plans and NOT Marketplace options.

“W’sup?” at TRIOweb.org

There is so much going on in the world of transplant and organ donation, whether it be on TV talk or news shows, the daily newspaper (for those who still get them delivered) or the many web-based information, blogs and news sites. TRIO members are recognized in their local communities as someone involved or even an ‘expert’ on organ donation and transplant, and thus you are in a unique position to correct misinformation and give living testimony to the success of transplantation and the urgent need for life-saving organ donation registrations and living donors.

With daily breaking news, how can you keep up with it all and thus carry out that heavy responsibility? TRIO’s answer is the daily news service offered on our website (www.TRIOweb.org) with now hundreds of current and archived articles, videos and links for your use. It’s all that and so much more, as our web re-designers are discovering as they grapple with how to make a user friendly website out of those many resources. In that regard, we expect to see the new site in the next two months with a fresh look and feel, more people-focused, easier to navigate and find what you may be looking for, highlighted with TRIO chapter/member photos.

“**YBSW?**” - We still need your help in sending in more TRIO-related, people-centered photos to support that re-design effort. Help by sending that .jpg formatted photo to info@trioweb.org today so we can consider it for use when the site is ready.

Don’t forget that web address: <http://trioweb.org>. Check it out today.

You are invited to submit your own contribution of a story or ideas for articles by sending your information to info@trioweb.org

TRIO E-News: a \$50 Opportunity?

“Did you get that kidney survey opportunity to help others and make \$50 in the process?”

That was just one of our recent monthly and special E-News issues offered to over 700 TRIO members with e-mail addresses in our E-News distribution list. If you aren’t seeing the monthly TRIO E-News in your on-line mailbox, that means we don’t have your email address to send it to you directly.

Concerned about privacy? We never give out your information, but if you don’t want to share your e-mail address, you can still see those electronic newsletters on line at TRIOweb.org, where they remain posted for 30 days under News from TRIO National. These monthly mailings are both colorful and informative, designed to be fairly short, with just a few articles of current interest, filling in the gap between the daily news updates on TRIO’s website and this quarterly *Lifelines* hard copy newsletter.

“**YBSW?**”: Send your e-mail address to info@trioweb.org to be added to this monthly distribution and stay on top of TRIO activity and important transplant world news.

Presentation Library Titles Continue to Grow

In recent months, four new titles have been added to this 5th year of our Transplant Presentation Library:

- **Program #54: “My Life As a Transplant Social Worker” by Liz Shore, MSW, CSW**
- **Program #55: “Sharing Your Transplant Story: One Example” by Jim Gleason**
- **Program #56: “Paying It Forward: A Transplant Story” by Clint Burns**
- **Program #57: “The Million Dollar Heart: A Transplant Story” by Janet Dennis**

“**YBSW?**”: Watch and be inspired and educated by these programs that can be viewed on your home TV or PC. While these titles will be future distributions, sent to your chapter librarians as part of the bi-monthly mailing of two DVDs, today you can check the TRIOweb.org site, under “Communications/Resources,” for a listing of 53 other titles currently available. Remember, if you see an interesting upcoming presentation at your chapter, suggest that it be recorded and submitted for library consideration and be sure to ask for the DVD library to be displayed at chapter meetings for everyone to use.

Life and Death Decisions About Who Gets Organ Transplants

A story out of Newtown Square, PA, is known to many millions of people: Sarah Murnaghan, now 11 years old, received two lung transplants in June after highly emotional attention in news and social media and a public debate over the merits of transplant allocation policy. Sarah has end-stage cystic fibrosis, and a judge ordered her added as an equal to the adult and adolescent lung transplant lists when she was originally at the bottom of those lists because she was too young.

Every thinking, feeling human being should wish Sarah and her family well in her continued treatment and recovery.

But some facts have been largely overlooked: In the months since Sara Murnaghan's story first gained public attention, about 5,500 men, women and children received transplants made possible by the generosity of deceased donors and the work of the national transplant network administered by the United Network for Organ Sharing. Sadly, about 1,500 others awaiting transplants died because no donated organs were available to meet their needs.

When confronted with a large, tragic situation, we often seek personal meaning in the story of one person, such as a child. We can't grasp the immensity of the earthquake and tsunami that struck the Indian Ocean in 2004. We can, however, e-mail to our friends the pictures and stories of the children who were rescued and need to be re-united with their families.

I, too, see transplantation in uniquely personal ways. I received a heart transplant nearly 20 years ago. My wife lost an adolescent son, who helped save and enhance other lives through organ donation. I am president of Transplant Recipients International Organization (TRIO), a group devoted to addressing the needs and interests of transplant recipients and their loved ones. I also am a member of UNOS' Board of Directors, which votes on national organ transplant policies. We decision-makers are not thoughtless, faceless bureaucrats. We are donation and transplant professionals, transplant recipients, living donors and relatives of deceased donors.

We all are informed by strong personal experiences, whether first-hand experiences like mine or the relationships that transplant doctors have had with hundreds or thousands of patients. We want to ensure that as many people as possible have the chance for renewed life through transplant.

As much as we are moved by our personal emotions and opinions, to have a national system that is fair to the needs of more than 119,000 transplant candidates, we must also weigh carefully what medical experience and data suggest will be the most effective and beneficial policy, given the supply of organs we have today. We do not take lightly any decision we make, knowing that as long as there is an organ shortage, some people in desperate need will benefit and others will not.

Allocation policy can and will continue to change as needed to help candidates with the organs we have available. But the larger lesson is lost in the focus on policy. Every transplant begins, not with a policy, but with a personal commitment to save and enhance the lives of others through organ donation.

You can decide, right now, whether someone needing a transplant will live through your decision to be an organ donor. In fact, your decision can help save multiple lives: in some instances, as many as seven organ transplants can be made possible by one donor.

If the nearly 100,000 people who signed the change.org petition, asking for a policy change for Sarah Murnaghan, continue to advocate for organ donation by committing personally and by getting ten more friends and family members each to make the same decision, that would be a potent force in Sarah's honor, to ensure that the next person in need (perhaps a child, or a grandparent, or a veteran, or a first responder) will have the same opportunity for renewed life and health.

It would be a great tragedy if, as we all take justifiable comfort in knowing one person's needs have been met, we lose sight of the many who still can be helped and the role we all can play in helping them.

[The above is excerpted from an article written by Jim Gleason and first published in the Pittsburgh Post on September 17, 2013. To read more, go to

<http://www.post-gazette.com/stories/opinion/perspectives/life-and-death-decisions-about-who-gets-organs-703631/#ixzz2f9fgcc52>

Recommended Reading and Viewing

Several new books have been added to TRIO's on-line database in recent months: patients sharing inspirational life stories of courage and recovery against heavy odds. Read reviews on our website for "Heart of the Game" about the first heart transplant recipient to return to playing professional sports back in the 1980s (and now COO for the Las Vegas OPO!) and "I left My Heart at Stanford" in which Don and Mary Cooper share their heart-felt story of survival.

For those who prefer to sit back and watch, instead of read, try "The Grace Card," a dramatic living kidney donation story. It is a powerful message. The Philadelphia Chapter "movie night" audience highly recommends it for home (Netflix or purchased DVD) or group viewing.

Membership – NEW or Renewal: **TRIO membership is renewable as of January 1 each year.**
Please support TRIO and its important work on behalf of transplant recipients, donors, candidates and their families by joining us in this important endeavor. Thank you for your support of TRIO!

Name of Member: _____

Names of other family members: _____

Address: _____

City: _____ ST: _____ ZIP: _____

Phone: _____ Fax: _____ email: _____

YES, I wish to receive *Lifelines* mailed to the above address. OR: YES, I wish to receive *Lifelines* by email

Member is: ___ Recipient; ___ Donor; ___ Candidate; ___ Family Member; ___ Other: _____

Recipient Profile (Optional): _____

Type of Transplant	# of Transplants	Date(s) of Transplant(s)
_____	_____	_____
Name of Transplant Center(s)	City, State	Time Waited

Donor Profile (Optional): _____

Type of Donation	# of Donation(s)	Date(s) of Donation(s)
_____	_____	_____
Name of Transplant Center(s)	City, State	

I would like to participate on the _____ TRIO Committee. Please contact me.

Annual Dues: Member at Large \$20.

Additional Contribution \$ _____.

TOTAL enclosed \$ _____.

Thank You for your tax-deductible donation!

Make your check payable to and mail to:
Transplant Recipients International Organization, Inc.
2100 M St., NW, #170-353
Washington, DC 20037-1233

PLEASE NOTE: If you are a member of a TRIO chapter, please pay dues to your local chapter instead of submitting this form. If you are not a member of a TRIO chapter, please consider joining a local chapter to receive the many benefits of chapter affiliation. TRIO national strongly supports local chapter membership. A list of chapters is available on our website www.trioweb.org. OR: consider starting a transplant support group or TRIO chapter in your area (contact info@trioweb.org).

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