

# Aspire

A PUBLICATION OF THE ACTIVE SURVIVORS NETWORK

SUMMER 2005 VOLUME 02

## The Second Running of the **SURVIVOR HARBOR 7**

**John Supsic**

2004 Survivor Harbor 7 Winner  
and Leukemia Survivor

## **Doug Ulman**

The Man Behind the Scenes  
at The Lance Armstrong Foundation

## **Water Training**

The Positive Benefits for Survivors

## **PLUS**

- SURVIVOR DIARY
- CORE TRAINING
- SURVIVOR  
ROUNDTABLE  
CONFERENCE

# Aspire

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## Director's Notes



### We are lucky for a number of reasons:

1. It's a great time of year. Spring weather is cooperating. There is more daylight, which means there is more time to get outside again.
2. The second running of the Survivor Harbor 7 is in June. This issue has details about why we started this event and how it is different than other running races. Many of last year's age group winners are back, including the overall and survivor men's division winner John Supsic. Also joining us is Heather Hanscrom, 2003 Marine Corp Marathon winner.

3. John Librett, a Health Scientist from the Centers for Disease Control, has agreed to moderate our Survivor Roundtable Discussion in June, a very important conversation about the state of survivorship. Some of the most knowledgeable and motivating speakers will participate on our panels, including representatives from the National Rehabilitation Hospital, the American Medical Athletic Association, the University of Maryland Medical Systems, LifeBridge Health and Fitness Center and CareFirst Blue Cross Blue Shield.

4. We are growing. The Active Survivors Network and Aspire magazine have more sponsors, partners and advertisers that believe what we are doing is timely and truly important. And our membership is growing. While there are so many survivors that have yet to hear about us, we are starting to make a difference, one survivor-at-a-time.

5. We are improving. Each month we learn about what we need to offer. As an example, we will add a new element to our website [www.ActiveSurvivor.org](http://www.ActiveSurvivor.org). We will offer a categorized section about recovery information from all kinds of survivors. So, when people are looking for members with similar health and training issues, they can learn from other athlete's and survivor's stories.

As survivors, we feel lucky for every new day. As athletes, we feel lucky for the hope that spring gives to us. We feel great to bring another Aspire magazine to print and we hope something in this issue will inspire you and help you to Aspire to be the best athlete you can be.

Jay McCutcheon, Active Survivor & Director



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## Healing Water

By Kay Carney

Athletes in pain and struggling with injuries and disability often come to the pool because other training environments have failed. Snippets of conversations can be heard around the pool illuminating what brings each of these survivor athletes to the water. After years of drugs or surgeries, water becomes the medium of healing, even though water is not immediately sought as a treatment.

The more conventional practices of modern medicine seem to be exhausted before water exercise is recommended, whereas in other parts of the world, water is an integral part of healing and maintaining good health. In the United States, we have just begun to look to water as a resource for overall fitness and wellness.

The aquatic environment naturally provides support as well as resistance in all directions of movement. Water reduces impact and allows for a greater range of motion and flexibility. In the following paragraphs, we provide a list of the properties of water and will provide more specific

reasons why water is so beneficial to a survivor's training regime.

- Buoyancy is an upward thrust that acts in the opposite direction of gravity. At hip level a person is 50 percent buoyant, at chest level 65 percent and with shoulders submerged 90 percent. While walking in chest deep water an athlete carries 50 percent less of their body weight. This effect can alleviate a fear of falling for survivors whose balance is compromised. It can also minimize joint pain when even low-impact exercise is painful and this supportive environment raises confidence and self reliance.
- In shoulder deep water, hydrostatic pressure assists venous return and shifts 60 percent of the blood flow to the heart. This increases heart stroke volume by 32 percent and slows the pulse by 10-17 bpm. This longer filling time allows the heart to work with less stress. Hydrostatic pressure also helps to reduce edema (especially when combined with exercise). This is beneficial for athletes with swelling in legs, arms or ankles and provides increased circulation.
- Viscosity is the internal friction specific to fluid. There is more friction when moving in water than when moving on

land. This friction provides resistance with water exercise, which can be easily adjusted. The faster the movement through the water, the more resistance there is. Water provides variable resistance to movements in all directions. This encourages the use of core muscles for balance and strengthening and promotes trunk stability and postural alignment.

- Viscosity and hydrostatic pressure provide built-in progression since greater effort meets greater resistance. In other words, the harder you push, the harder the water pushes back.
- Movement through water creates turbulence that challenges the body's ability for balance and proprioception, our sense of the position of our body parts, relative to other neighboring parts of the body. Turbulence stimulates an increase in blood flow to independent limbs, invigorates and energizes. Turbulence can be used to intensify exercise, increase muscle activity and provides opportunities to build strength.
- Water is often the kindest environment. What is not possible on dry land, supporting weight and maintaining balance, is suddenly achievable. Since results are achieved more quickly,

survivors have a feeling of greater accomplishment. A sense of active participation in the rehabilitative process also leads to improved self-esteem and decreased depression.

### Here are three water workouts that are much more than just swimming.

#### Water Walking

Begin in waist to chest deep water. If you are exercising for cardio-vascular fitness, the water temperature should be approximately 78 – 82 degrees. If you are just beginning an exercise or therapy program, a warmer therapy pool of 90-94 degrees may be appropriate. You will need a level bottom and very little depth variance. Water shoes can help protect your feet from a rough pool bottom and provide stability against slippery tiles.

Walk in the water much the way you would on land, heel to toe, arms swinging in opposition. There is a temptation to stay on your toes (especially in a fitness pool, because you're probably cold when you begin) but resist this. It will lead to extremely sore calves and be counter productive to mimicking land-based walking. Don't worry if this is awkward at first. Doing something different than you've done it your entire life often is awkward. Relax and you will acquire a natural rhythm.

The length of your water walking session depends on your recovery and your fitness level. Start small and assess how your body reacts.

#### Variations to water walking workouts:

- **Backwards walking:** Land on your toes and roll to your heels, arms in opposition, palms forward, assisting motion with a gentle forward sweeping motion.
- **Lateral or sidestep walking:** Step to the side, just wider than your hips. Press out with your outer thighs and squeeze in with your inner thighs. Arms assist, palms in towards body, reaching wide

in time with step and squeezing water towards body at closing.

- **Intensity variations:** Use the pool clock or a watch to time your lengths. Alternate one length easy with one hard length. Add resistant equipment like gloves or dumbbells to increase intensity and to add resistance and workload.

#### Shallow Water Running

Running or jogging in shallow water is excellent cardiovascular work, but good form is imperative. If you are using this workout to replace a run or while you regain the ability to run on land, you want to mimic your running style as closely as possible. Again you will be tempted to run toe to heel. Driving your heel down against buoyancy can be tricky. Think more of gliding forward with your flat foot, pressing your shin against the water in front of you and placing your whole foot down simultaneously.

Getting the technique right can be frustrating, but if you really want to run again and this is your best option for some weight bearing, it's worth the effort. Once mastered this can be an extremely challenging workout! Remember, the water hits back, whatever you give it, it will throw right back at you. Don't be surprised when you start sweating.

#### Deep Water Running

During deep water running and other deep water exercise, you are suspended vertically in the water with the support of a buoyancy belt or floatation cuffs around the ankles.

Fix a buoyancy or floatation cuff tightly because the fabric will expand when wet and become cumbersome. Allow yourself a

moment in the water to assess whether you have chosen the correct equipment to keep you comfortably buoyant. In general, the fitter, leaner, more muscular you are—the less buoyant you will be.

Manufacturers make larger, more buoyant cuffs and extra buoyancy pieces for belts. Experiment with different equipment to find what works best for you.

While deep water running, you should hold a five-degree tilt forward with your whole body with no bending at the waist or hips. Your knee will rise high, with a flat foot and drive down and back, finishing with a gluteal squeeze in the corresponding buttocks. Arms should swing comfortably at your sides, thumbs up, with a soft cup, pulling water straight back, assisting forward movement.



It will seem as though you are moving in slow motion and take a lifetime to reach the other end of the pool. Remember water has 12 times the resistance of air, so it will naturally take longer to travel through it. In trying to compare a land-based run to deep

water running, use time, not distance. Experiment with translating your land-based run workouts to water. Sprints, paced runs and intervals are all possible.

For more water workout options, explore your local fitness and recreation center. Also look for an Arthritis Foundation certified course near you.

*Kay Carney is a certified aquatics trainer by the Aquatics Exercise Association and Arthritis Foundation and has won numerous awards for the development of an eight-week water training course. You can reach her at [Kay.Carney@comcast.net](mailto:Kay.Carney@comcast.net).*



## Running to Survive

### A Caregivers Perspective

By Michelle Ave

**A**s an athlete, most things in life relate back to training and the skill set I developed. My ability to deal with struggle and persevere, the ability to not only be hopeful but confident in the sight of the unknown, I learned as a runner. Coping skills if you will. I now know that those skills prepared me for more than an 800 or 1,500m around an oval track, but for life itself.

I am so fortunate to know Steve. He is more than my husband, he is my best friend and my world. We share everything. We felt it might be important to share our thoughts with others who know the struggle and that we might be able to suggest, if only for a moment, a different perspective which others helped me to see. These moments, for me, were milestones in the process of healing and understanding.

**I**n August 2003, Steve a former sub four-minute miler had signed up to run Chicago marathon. While training Steve had experienced mild pain in his left femur. He believed it could be a femoral stress fracture and decided to get an x-ray. After the x-ray, the doctor tells us that the x-ray image shows a growth in Steve's femur although his blood work is normal. My mind gave me a number of most likely instances for the growth within in his leg—an injury as a kid on a mountain bike, skateboard or over use as a runner? We are referred to the Oncology Department at Mass General Hospital.

One of the most difficult times for me was the first few weeks as we began to uncover what we were dealing with. It was much like the time before one begins to warm up for a race – when the outcomes

of the event are darting in and out of your mind. It isn't until you are in the familiar routine of the warm up that you are grounded once again.

In September 2003, Steve is scheduled for a biopsy. In my mind the test would reveal a benign growth. However, the results of the biopsy are inconclusive and as I stand at Union Station in New York waiting for a train back to Boston, Steve informs me he will need surgery.

**T**he next appointment with Steve's orthopedic oncologist brings us back to Mass General Hospital on a beautiful sunny fall New England day. Steve and I are laughing about something in the waiting room and with Oakley sunglasses and Reebok athletic clothes, I imagine we do not fit the usual suspects for serious medical news.

Four doctors review Steve's recent x-rays and inform us about the possibilities of the growth. Although the biopsy was inconclusive, the teams' opinion is that it is not benign. Steve's first comment was "Okay, can't you just take it out?" Most patients ask, "Why me" or "How could it be." He just said, "Let's just take it out." A pit begins to form in my stomach as the doctor discusses with us the fact that surgery is a definite. Yet to be determined is how invasive the surgery will be based on the growth type and size. Surgery is set for Friday, Oct. 3rd.

One morning at the office, a coworker of mine asked if I had any new news and I told her we wouldn't know until the day of surgery. She looked at me and said with one hand on my arm – "Michelle, no matter what the outcome you are both going to be ok." I looked at her and for the first time I had a rope to grasp. I was so focused on the best-case outcome that the reality of the alternative was not explored. How would this be okay? It was at this point that I allowed myself to consider Steve's story as a success story.

The physician emerged from the seven-hour surgery to reveal that they had removed 6.5" of Steve's Femur bone, with Osteosarcoma in it. That means he is, in theory, cancer free. His surgeon says that Steve's bones are the hardest he has ever experienced—like granite, a positive byproduct of years of running. He now has a bone graft and three stainless steel plates in his leg. It wasn't until that morning when we visited Steve in the hospital and I am able to see him and see

his leg that I know we are going to get through this.

Back at the office later that week my coworker came to me again and asked about Steve. She said to me; “So you never knew Steve with cancer. They removed it while you were sure it was not cancer and now that it is out, he is cancer free.” This was very true.

We had a good deal to be happy for and this is where I chose to rest my emotions. The next step was going to be less like a sprint and more like a long tempo run. The sprint for me was the stage of learning about the cancer. The chemo treatments would prove to be the true endurance training.

**C**oncerns about what the insurance would cover began to enter my mind. Are we covered for the hospital visits and treatments? Yes. What if there are more hospital visits than normal. Yes, all hospital visits and treatments are covered. By the time I was done with the phone call I was confident all I needed to concern myself with was getting Steve through this and moving on. In the back of my mind, no matter what, I somehow knew he was going to get the care he needed even if we needed to find a way to pay for it.

My family reminded me how strong Steve is and told us we would laugh at some of the things he said and did later. Like the image of him on the spin bike early one winter morning. He was wearing slippers and a long robe and riding like a champion. My brother began to call him Heff, short for Hugh Heffner.

I can recall sitting in my car one cold evening on the phone with my Mom. She said to me that she was ready to come out and stay with us as long as we needed. I was able to relax once again in this moment – knowing that should I need to call on her, she would be there. It was a feeling that confirmed for me that I was not alone to deal with this.

I couldn't buy Steve enough things

when he returned from the hospital after surgery. Both of Lance Armstrong's books were a must. Buying little gifts was my way of wanting him to feel good. I bought every book or CD I could find. He finally told me he couldn't read all these books in two years let alone the months to come. He just wanted me to be there.

I also recall the first time I went for a run after Steve had returned from the hospital. For about two minutes I thought I shouldn't run knowing how much he wanted to run and not knowing if he would ever run again. I didn't share this with Steve. I just laced up my shoes knowing he knows me better than I know myself. Moments later he yelled out to me that I should get out and run.

**A**long the way I was to encounter individuals who would share a story or insight they might not have if we not been going through this ourselves. Cancer is and continues to be taboo. Once you are a member, people reveal themselves to you from the most unusual places. Friends from work and people who ran told us stories. I learned that if I could find one person who could do what we were about to attempt – there was hope. More than hope there was a mind set and level of confidence measured in our sheer will to succeed. New limits are set each day. Some are there to remind us we too can succeed, others like Lance show us that not only can you succeed, you can thrive. We plan to thrive

In October 2003, we are at the Reebok Sports Club in downtown NY presenting to the running vertical publications and retailers at the NYCM. My brother is with Steve who is getting a port put in his chest and will receive his first dose of chemo on the 29th. It seems like any other workday but I know different. After today this pure and extremely fit body will be filled with



poison. Again I am drained of emotion and energy. How can this be happening to us? Almost as quickly as this thought enters my mind the next is clear and like

the sound of a coach telling me to pick it up. This is going to ensure his future is long and happy. This process is saving his life and I need to embrace it for what it truly is. Steve was slated to have chemo treatments for six to ten months.

On Halloween weekend our first encounter with chemo is a mixture of surprise and struggle. I was surprised to pick him up at the hospital and see him looking like his old self. He gets on the phone on the drive home to check in with his Mom and friends. He feels okay although a little nauseous.

Life is going on all around me but I seem to have slipped into a confused and agitated state. The bottles of pills are on the dining room table – what looked like a sea of pill bottles. Before me a release form with scheduled times and doses. The names of the Meds were not consistent with the bottles I had received from the pharmacist. What pill is what and when do I need to give these? I am drained and tired. My brother suggests a way to keep it simple. We go to the computer and create a schedule. We can do this.

That Sunday morning, Steve wakes up and would like to shower. That is a good sign. He decides to watch the New York City Marathon on TV and I head outside to begin planting the 50 red tulips I had bought weeks ago. I call my Mom as I am planting. It's going to be okay.

That afternoon Steve begins to have an allergic reaction to his initial chemo treatment, from the drug, Methotrexate. He was beginning to hallucinate. He could not keep food or water down and I began to wonder if this was the picture of things to come for the next nine months. By the end of the day, I was arranging to bring

Steve to the hospital on Monday.

Due to a very toxic reaction to his first chemo treatment, Steve spent an un-scheduled week in the hospital. I could relax in this moment as he was under watchful eyes.

By the second month, Steve had lost his hair and was puffy from the chemo treatments. When he was asked to speak at a dinner banquet for a New England running club, he was on crutches with no hair. I wasn't certain what to expect but encouraged him to do the dinner and enjoy it. He got up in front of a crowd of runners and talked about his career and how much running means to him. He had them laughing and hanging on each word. Steve was still there just a little less hair and energy. After his speech he had people coming up to wish him luck. One woman came over and told us she too was a cancer survivor. She looked normal and full of energy. She said, "this time will pass and you will feel normal again. This is not your defining moment or who you are but a part of the healing process." I hung onto those words and visualized us saying the same thing to another survivor in the future.

The weeks to follow began a series of routines, which took on a form not that much unlike a training schedule. We knew that one of the two cycles he would receive every third week would be more difficult than the other.

Four months into the process and we began to believe this was manageable. The wonderful care he was receiving from MGH and the fact that he had to stay over night each time he went in – either two nights or five depending on which cycle he was on. I was able to stay with him until late in the evening when I would return home.

It's okay to be sad and emotional. For me every night I would leave the hospital I would feel very emotional. It was just me in the car with my thoughts and a time I allowed myself to feel the depth of pain we were going through. By the time I would reach home however I would be


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ready for the next day and whatever it was to bring. Like the coming of each season, this too will pass and we are going to be stronger for it.

Monthly statements would roll in from our health insurance company. It was truly amazing how much the process was costing. I kept reminding myself that at the end of all this we needed to thank a lot of good people.

The chemo treatments were part of an overall plan for Steve. There were no signs of cancer after surgery however, as precaution and a preventative measure, the chemo was strongly recommended. This wore in the back of our minds over the course of the next four and a half months – the most difficult time began at month number six. The side effects were now stronger and lasted longer. Steve's body

was no longer able to diminish the results of the treatments.

By spring the tulips were coming up that I had planted some six months ago. A sign to me that time was in fact passing and there were a lot of good things to look forward to. Within two treatments of the completion of his chemo regime, it was apparent the drugs had exacted a toll on Steve's body. His tri-weekly blood work results kept pushing the next treatment away for another week. Some times this news felt good to me, because, each time the treatment was delayed I got more and more of Steve back.


On July 15, 2004, the last treatment day was here. It's hard to put into words how thankful we were for Steve's fitness going into this and his ability to do something about what he thought was just a mild pain sooner than later.

Running has and continues to be a central theme in our lives. Running put us both through school, showed us the world and taught us skills, which would help us succeed in life. It's how we came to know each other and in this instance, soon I began to realize it might have been what saved his life.


The next challenge for us was to get Steve walking again after eleven months on crutches. His leg had shrunk however the bone had fused with the graft. The doctors were marveled and delighted. The growth was very unexpected due to the invasive chemo treatments on the healing process.

A month after his last treatment, Steve received his walking papers! He was in fact ready to begin the process of rehab and to begin walking. As much as we looked forward to this day and to the close of the process, we both felt a little like we weren't quite ready to let go of the doctors and nurses who had become a part of our success.

Steve's last office visit with his surgeon was on September 10. We were silently so extremely thankful for every day. Our surgeon had told us we would learn to cele-



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brate the small things in life like we had never known. At that time I wasn't completely certain I liked that but now I intimately understand the significance of this statement. I find that I don't want to dwell on it for we are so fortunate to be moving forward in good health. It is still too close to want to go back.

Steve is now walking, his hair has begun to grow back and he is regaining his ener-

gy. He is back only better in my mind. I am amazed how we are learning to distance our thoughts from last year this time. Now and again someone's words of wisdom ring true and I have to smile. I am hopeful that someone will find a moment of comfort in something I have said or learned along the way. We have grown stronger in the struggle and wiser in the knowledge of how special each day is.



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## 2004 Results - Baltimore, MD June 12

### Open Division

#### Male

Place	Name	Age	City/State	Time
1	John Supsic	25	Boulder, CO	35:02
2	Michael Wardian	30	Arlington, VA	35:20
3	Eric Furst	23	Ellicott City, MD	37:37

#### Female

Place	Name	Age	City/State	Time
1	Lee Dipietro	46	Baltimore, MD	41:47
2	Denise Knickman	36	Baltimore, MD	45:28
3	Karen Smyers	43	Boston, MA	46:10

#### Male Masters

Place	Name	Age	City/State	Time
1	Stephen Dillard	40	Baltimore, MD	41:39

#### Female Masters

Place	Name	Age	City/State	Time
1	Linell Smith	51	Baltimore, MD	51:22

### Survivor Division

#### Male

Place	Name	Age	City/State	Time
1	John Supsic	25	Boulder, CO	35:02
2	Marc Riseling	38	Memphis, TN	41:52
3	Thomas Johnson	38	Arnold, MD	43:55

#### Female

Place	Name	Age	City/State	Time
1	Karen Smyers	43	Boston, MA	46:10
2	Heather Koczur	32	Oakton, VA	51:12
3	Michele German	36	Lutherville, MD	56:06

#### Male Masters

Place	Name	Age	City/State	Time
1	Patrick Gary	53	Millers, MD	48:18

#### Female Masters

Place	Name	Age	City/State	Time
1	Nancy Love	42	Blacksburg, VA	58:15

## Race Overview

# Survivor Harbor 7

## The first race with a competitive division for Survivor Athletes

By Jay McCutcheon

In communities around the world, athletes of all abilities and ages have incredible opportunities to compete. However, there have been very few efforts to include athletes who are survivors of life-altering medical conditions such as cancer or stroke in a manner that fosters high-level competition. That is why we started the Survivor Harbor 7.

Despite the proliferation of events, which raise the public's consciousness about specific afflictions or diseases, there are no separate categories to honor the athletic achievements of survivors—only age group awards for each gender. Nor are there competitive venues for survivors to be measured head to head against other survivors. Also, no one has ever kept a database of survivor

records in any distance, sport or significant athletic accomplishment.

Running events include venues from track and field to ultra-marathons. A race can be a means to a vacation destination or a means to test the limits of mental and physical endurance. Events have fostered participation by relay teams, corporate teams, and teams of the same ages or sex. And more recently, major races and small-town events have become more inclusive. Runners with special needs (vision-challenged, wheelchair competitors, amputees, special Olympians) are often highlighted and accommodated.

The Active Survivors Network and the Lance Armstrong Foundation took the

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### Race preview for 2005

At this year's second annual race, expect to see double the numbers from last year's field of 830 to 1500 runners. A new four-mile run/walk has also been added for less competitive athletes. John Supsic, a leukemia survivor, was the only athlete to double in last year's race. He won both the men's open division and the survivor division and he will return to defend his title in 2005. With twice as many athletes there will be more competition for individual age groups in 2005 (See last year's winners and the event fact sheet on these pages.) For more details about the race, go to [www.ActiveSurvivor.org](http://www.ActiveSurvivor.org).

### 7 mile race / 4 mile run/walk Survivor Roundtable / Party June 11 and 12, 2005 Event Fact Sheet

#### *Survivor Harbor 7*

A seven-mile race around the Harbor.

#### *Fitness Run/Walk - New for 2005!*

A four-mile run/walk at Harborplace Ampitheatre.

#### *Pre-Race Party*

Pre-race pasta party.

#### *Survivor Roundtable Conference- New for 2005!*

Discussing the needs of survivors and their families.

### Race Format:

Point-to-point, chip timing, handicapped accessible.

*Seven-mile race from Tide Point to the Can Co. in Canton.*  
*Four-mile race from Harborplace to Canton.*

### Participant Costs:

*Party* - \$18 per person  
*Race* - \$25 advance;  
\$30 after June 1, 2005  
*Survivor Roundtable* - Free to the public.  
Must register in advance

### Dates and Times:

*Survivor Roundtable* - June 11, 2005  
1:00 PM – 5:00 PM

*Pre-Race party* - June 11, 2005  
5:00 PM – 9:00 PM (location TBD)

*Seven-mile race* - June 12, 2005  
7:30 AM (Tide Point to Can Co., Canton)

*Four-mile run/walk* - June 12, 2005  
8:05 AM (Harborplace to Can Co., Canton)

*Post Race Party* - June 12, 2005  
8:30 AM – 10:30 AM (Can Co., Canton)

continued from page 9

lead in establishing a system for promoting high-level athletic competition for survivors. People who have been affected by life-altering conditions such as cancer, stroke, cardiac arrest, autoimmune disease and accident survivors will be eligible for awards in the Survivor Harbor 7 by gender and by age group. The Active Survivors Network will then keep records of achievement by these survivors. These statistics will serve to motivate other survivors to achieve higher levels of performance. The data will also motivate more survivors to participate. Highlighting the awards and rankings will generate public interest and greater awareness of survivors' achievements. This initiative will promote more widespread participation by the survivor community and ultimately, impact

the health and quality of life of survivors by encouraging greater levels of fitness and participation in competitive sports.

Lance Armstrong, a cancer survivor and winner of six consecutive Tours De France, Karen Smyers a two-time world triathlon Champion, and Heather Hanscom, a brain tumor survivor and winner of the 2003 Marine Corps marathon, are exemplary survivors who have regained elite athlete status after winning their respective battles against disease. These are a few of the more publicized and well-known survivor athlete stories. There are thousands of other survivors who should be encouraged to compete and be recognized for their efforts and accomplishments.

Some charities have focused on athletic events to motivate donors and partici-

pants. These charities get pledges and donations from runners, walkers, cyclists and swimmers to help generate funding for disease-specific causes. Charity events include: Teams in Training for leukemia, Race for the Cure for breast cancer, biking for multiple sclerosis, walking for brain tumors, aids, arthritis and diabetes. These events have led to a heightened awareness of illness. They also have served to motivate participants to train and become fitter and faster for a good cause.

The Active Survivors Network has developed the Survivor Harbor 7 for survivors who run. While it is open to all runners, this race is the first of its kind with divisions for survivors to compete head-to-head. The hope is to encourage athletic achievement and promote greater levels of fitness and pride in the survivor-community.

## 2005 Weekend Activities

### Survivor Harbor 7 Race

Over 800 participants attended the inaugural event in 2004. The first and only race permitted and held on Downtown Baltimore's waterfront promenade, from Tide Point to Canton, it is also the first race in America with a survivor division for athletes living with chronic disease or recovering from a catastrophic illness. Last year, survivor athlete John Supsic won both the survivor division and the open division with a time of 35:02.

The 2005 event will be moved to Sunday, June 12, 2005 to accommodate out of town participants. The same course will be used again and the field is expected to grow to 1,500 runners.



### 4-Mile Fitness Run - New for 2005!

A 4-mile race will be added this year to accommodate some runners and walkers who choose not to run the seven-mile race. The 7-mile race begins at 7:30 AM and the 4-mile run/walk begins at 8:05 AM. The runners and walkers will finish in Canton in time for the post-race reception.

The four-mile distance will be jointly promoted by the Get Fit Maryland campaign developed by the University of Maryland Medical System. This 12-week fitness program will culminate with the four-mile Survivor Harbor race.

### Survivor Roundtable Conference

A survivor roundtable will be held June 11, 2005 to open dialogue between two groups, survivors and the medical community. The roundtable will include over 160 survivor athletes who are expected to participate in the Survivor Harbor 7 weekend from all parts of the country. The roundtable will hear survivor opinions, needs and provide information.

ASN and AMAA will manage the roundtable with key speakers from the medical community. The conference is moderated by John Librett, Health Scientist of the CDC.

### Race Party - New for 2005!

A pre-race pasta party, held on Saturday, June 11, 2005, in an outdoor setting will include live music and food, a silent auction, vendor displays, merchandise sales and other activities. The celebration will be held at a location to be determined and open to the public.



## Survivor Roundtable Conference

**L**ance Armstrong has made survivorship fashionable. He has brought the idea that disease need not be a death sentence and while not all survivors enjoy the recovery Lance has seen, he has focused attention and energy on the growing number of survivors in this country.

Some estimates suggest there may be as many as 88 million Americans who have overcome or are living with the effects of cardio vascular disease, cancer, MS, AIDS, arthritis, lung disorders, diabetes, serious accidents and a host of other disorders. While the exact number is not easy to define, our network has yet to come across anyone who hasn't been touched personally or know someone close to them who is a survivor.

That's why on June 11, 2005 the Active Survivors Network will host the 2nd Survivor Roundtable Discussion, sponsored in part by **CareFirst Blue Cross Blue Shield** and **LifeBridge Health and Fitness**. This four hour discussion will be held in Baltimore Maryland at the Renaissance Harborplace Hotel. The primary audience is the survivor community, caregivers, and family members.

The discussion will be interactive, with open dialogue between panel presenters and attendees. The program will be divided into four, 45 minute sessions and include the following topics.

### **The State of Active Survivorship in America**

How do Americans view survivorship? Media personalities and politicians use survivors and survivor stories to motivate and create emotion but for 88 million Americans who are looking for ways to recover, are there enough resources available to help with recovery? Are we prepared to handle the wave of survivors projected for the next decade?

### **Sports and Recreation - Can We Still Play?**

What role does the health club industry and therapists play with the changing nature of survivorship? What role do the disease non-profits play? What programs are available to survivors?

### **Young Survivors**

Does age matter? With increased medical technology, improved pharmaceuticals and earlier detection, we are seeing a boom of survivors under 50. Recovery for persons under 50 is measured differently today. There is an expectation from young survivors, to become more active after diagnosis. What is necessary to help these persons return to an active lifestyle? What role do groups like Young Survivors Coalition, the Active Survivors Network and others play?

### **Empowerment and Access to Information**

How to take control and find what we need about health and fitness. Many survivors are frustrated with the lack of information about their condition. How can survivors take control of their situation, their treatment and recovery?

### **Medical Professionals**

How do we navigate the abundance of information available from health professionals? How are MD's changing? How should they change?

### **Caregivers**

Support or patronizing, where is the line? What role do caregivers play in the recovery game? And how can caregivers ensure they avoid their own physical and emotional letdowns?

We will end the discussion with final thoughts, next steps and how to move forward with the information shared during the day and what role The Active Survivors Network and other organizations take to help facilitate action and more discussion. Results will be shared on our web site.

*The discussion is free and open to the public however participants must register in advance. To register or to learn more go to [www.ActiveSurvivor.org](http://www.ActiveSurvivor.org) or call 410-823-0562.*



# Survivor's Story

## Live Strong

By Doug Ulman

I remember the late night three-mile run with my brother vividly. I remember the wheezing feeling that lasted much longer than usual. The August night was humid and we sat eating Popsicles watching an Orioles game. My parents suggested I go to the emergency room if the wheezing persisted.

It did, and as we reached the emergency room that August evening, the events that transpired seemed to occur at an incredibly rapid pace. Several nurses and doctors conjectured what might be causing my breathing problem. Tests were run and finally an x-ray was taken. All signs pointed to a benign allergic reaction of some sort and I was sent home in the early hours of the morning.

I awoke feeling fine and I returned to coaching soccer at a youth camp the following day. When I returned from work I listened to a voicemail message that would change my life. My general practitioner said that I needed a CT scan that afternoon.

As I was being removed from the CT scanner, one image has stuck with me. Behind a glass window in a room with several computers and monitors a technician was pointing to electronic images of my chest cavity on one of the large screens while my mom stood behind him. At that point, I knew something was wrong.

A week later I had surgery to remove a portion of my ribcage along with a growth that doctors told me was most likely benign. In fact, they said that the chances of it being malignant were only two percent. As you might imagine, that was not the case, and doctors confirmed that the growth in my chest was more appropriately called a tumor. Two weeks later the pathology concluded that I had a very rare form of cancer called chondrosarcoma.

While the devastation of hearing the words “you have cancer,” lasted for days, my family and I quickly learned that I would survive. I returned to Brown University and joined my

**(left) Doug Ulman finishing the 100 mile Himalayan Stage Race.**

teammates on the soccer team so that I could try to get back to normal, or what I refer to as the new normal. After recuperating for nearly eight weeks I began jogging and then practicing with the team and eventually on October 11, 1996 I returned to the collegiate soccer field, an event that surprised many doctors who had told me I might never play competitively again.

I was the last one to leave the soccer field that night, surrounded by family and friends and I was mentally and physically exhausted, but the feeling of doing something physical I loved so much meant more to me than I can ever describe.

Later, while I was working on my career plans, I was inspired by a television program that discussed the need for more resources for the fight against cancer. Immediately, I called my mom and told her that our family needed to do something to give back to others who would have to go down the lonely road that I had traveled.

I thought about my own cancer experience and the frustrations I had encountered when I tried to find support for people my age. I wanted to change the way young adults were treated. It seemed to me that we were ignored because the focus was on young children with cancer and older adults (60% of people diagnosed with



***Doug Ulman (right) with Brock Yesto, current Executive Director of the Ulman Cancer Fund, which Doug started and remains the board chair.***



*I believe strongly that life is simply a grant of time and we have no way of knowing how large or small our grant will be.*

**DOUG ULMAN**

cancer each year are 65 years or older). Six months after my initial diagnosis, I was diagnosed with melanoma and three months later I was diagnosed with invasive melanoma. I experienced the same frustration, as I could not find other people my age to talk to.

I started The Ulman Cancer Fund for Young Adults from my dorm room. It was created to provide support, education and resources to other young adults who were also facing cancer. My family and I put our heart and soul into our newly formed organization in order to make the world a better place for young adults with cancer and as the organization began to grow, we realized we were truly filling a void in the cancer community.

The issues that young adults face are very specific to the time in their life that they are diagnosed. They are trying to become independent and yet they are forced to rely on other people. They are contemplating their future and they are forced to think only in the present time of their treatment. They have many friends, but many young adults who don't have cancer cannot truly understand. And worst of all, there were no programs or support mechanisms to help young adults facing cancer deal with these issues. The Ulman Cancer Fund for Young Adults developed as a way to ensure that young adults have a place to turn.

In late 2000 I decided to leave my full-time role with the Ulman Cancer Fund for Young Adults in order to take a job with the Lance Armstrong Foundation (LAF) in Austin, Texas. The reason that I ultimately decided to move to Austin was that there has never been a better opportunity to impact change. Armstrong has provided a platform for everyone who works or volunteers in the cancer community to elevate the issues. He stands as a shining example of what is possible after having cancer and he encourages all of us to work even harder to ensure that others will not suffer from this disease.

I am as committed as I have ever been to the issues facing young adults with cancer and the LAF, in partnership with the Ulman Cancer Fund for Young Adults and other organizations across the country, is undertaking bold new initiatives to truly change the way that young adults with cancer are treated.

**Here are just a few of the programs we are initiating:**

- Our public health department is working tirelessly to develop and fund community-centered programs that will provide much needed services for cancer survivors. We have also partnered with the Centers for Disease Control to ensure that each state's comprehensive cancer program addresses the needs of cancer survivors in their area. This partnership resulted in the development of A National Action Plan on Cancer Survivorship, which charts a course for public health survivorship activities across the country.
- Our research department is funding innovative studies to look at quality of life and crucial survivorship issues that will ultimately yield interventions allowing cancer survivors to live strong.
- Our advocacy program is giving more than 10 million cancer survivors a voice and ensuring that their needs are at the forefront of health policy.
- Our education program is working to bring awareness to the physical, practical and emotional issues that are often overlooked in the healthcare setting. We are working to bring awareness to the issues that cancer survivors face and we are educating the general public so that they understand that cancer is now a chronic illness for people who need ongoing support and resources in their battle with their disease.

I believe strongly that life is simply a grant of time and we have no way of knowing how large or small our grant will be. With that in mind, it is crucial that we live each day to the fullest. As the manifesto of the Lance Armstrong Foundation says:

**"We believe in life.**

**Your Life.**

**And that you must not let cancer take control of it.**

**Because we're passionate about helping you live every minute of your life with every ounce of your being."**

**Live Strong.**

*Doug Ulman is the director of the Survivorship of the Lance Armstrong Foundation and the founder of the Ulman Cancer Fund for young adults. He continues to play recreational soccer and finds time to also run marathons and play golf. (www.ulmanfund.org) Visit www.livestrong.org to learn more about survivorship issues.*

## Not Just Surviving But Thriving After a Stroke

In the summer of 2004, a catastrophic stroke changed the life of Beatrice Kallina, a respected executive business woman in the fields of law and banking. The stroke affected Beatrice's ability to walk and use of her left arm. The stroke also damaged her cognitive skills of sequencing and mathematical calculations. Beatrice recalls her frustration and had difficulty completing simple tasks of everyday life. "During my rehabilitation I had a hard time figuring out the sequence of making an ice cream cone and figuring out the change I would receive after making a purchase." Beatrice was fortunate that she received care immediately after her stroke and that the blood clot in her brain reabsorbed over time, minimizing permanent damage to her cognitive and physical abilities. Moving through rehabilitation to a wellness program helped Beatrice regain her lost skills and more.

After the acute phase of her stroke, Beatrice was enrolled in an intensive rehabilitation program that enabled her to say good bye to her wheelchair and enter into a new phase of rehabilitation. This new phase was critical to strengthening her body and improving her skills needed for daily living. Despite gaining back all of her mental acuity, Beatrice reached a plateau in her physical rehabilitation. She was told that she would benefit from a specialized program that would focus on her residual deficits and assist her in reaching her optimal functioning level. Fortunately, Beatrice found that Kernan Physical Therapy in Timonium, Md. offered such a program. Beatrice began a unique rehabilitation pro-



gram that included stimulation therapy for her hand with exercises to further improve her fine motor skills. The facility also offered state-of-the-art equipment for strengthening her left leg and foot.

While at Kernan Physical Therapy, Beatrice enrolled in the Well Life Program, a wellness program that provides a structured regimen of exercise and nutrition supervised by highly trained physical therapists, as a means to find support during her recovery. "Engaging in a regimented program can be scary for anyone entering an exercise program after a catastrophic event or while managing a chronic illness," says John Mahoney, physical therapist and founder of the Kernan Physical Therapy Well Life Program. "These individuals fear that they may experience further damage or experience another traumatic injury. In some cases individuals feel self-conscious or they think they won't be able to

handle working out. Or they believe they will fail at their attempt to get fit and healthy," He explains. It is not uncommon for individuals to believe that exercise just isn't in the cards anymore because of their illness or lingering problems from a traumatic event. Individuals can overcome these hurdles if they are in an environment that supports them no matter where they are in

their recovery by providing individualized, supervised regimens by experienced and knowledgeable physical therapists.

For Beatrice, Kernan offered her a safe place—both mentally and physically—to engage in exercises geared to strengthen her areas of weakness and also surround herself with other individuals with their own unique stories. Beatrice also knew the physical therapists cared about her, that they would watch over her and compassionately push her to new limits.

Wellness programs offer health improvement and an opportunity to focus on varying stages of recovery and survivorship. These programs also offer other services and resources that support stroke survivors. A robust wellness program usually offers an environment specifically for stroke survivors and other individuals who have chronic illnesses or who have survived a traumatic event. They are also a place where healthy individuals can find nutritional and exercise programs designed just for them.

The goal of wellness programs is to individualize a nutritional and exercise program based on extensive health and wellness assessments. Approaching care in this manner is an effective way to assist in determining an individual's specific needs for education and prevention and offers a roadmap to improving health.

*For more information about Kernan Physical Therapy Well Life Program call 1-800-492-5538 or visit [www.umm.edu/timonium/well\\_life.html](http://www.umm.edu/timonium/well_life.html).*

### What to look for in a Stroke Rehabilitation and Wellness Program:

- Comprehensiveness and an emphasis on meeting the unique needs of each patient
- Patient and caregiver stroke education
- A staff that is knowledgeable about stroke and completed specialized training in stroke rehabilitation and prevention
- A continuum of care

## Core Training: A Functional Way to Exercise

By Lauren Bunney



**A**s a survivor, it is essential to concentrate on how the body works and what to do to make it stronger. Core training focuses on the core, or midsection of the body, and has

proven to be a phenomenal way to improve overall body strength.

Because core training is based on the integration of many muscle groups outside your abdominal muscles and lower back, it requires thought and concentration, heightening the mind-body connection. In essence, the stronger the core, the more efficiently the entire body functions as one connected unit.

When we challenge the body with functional exercises, or movements that replicate day-to-day activities, the brain sends neurons, or messages, to the muscle fibers telling them to contract, which in turn moves the various bones of the skeleton. The more neurons the brain fires to the muscles, the more the muscles contract and relax. When the brain becomes more efficient at firing neurons and the body becomes better at receiving them, the results are a retraining of how the brain and body work together, helping to recoup functions that may have been lost or weakened.

Building core strength is essential to improving balance as well as to increasing the overall strength, flexibility and stability of the abdominal muscles and lower back. Furthermore, improvements to the core positively affect posture and functions of the body's muscle groups in other parts of the body too.

You may be familiar with what the fitness industry refers to as toys, which includes Physio-balls, balance discs and

Bosu balls. Incorporating these pieces of equipment into your exercise regime helps target the core and retrains the body to function efficiently. In addition, the use of Free Motion strength training equipment allows you to move within your own range of motion while increasing your range as you become stronger and more agile. These fitness toys give you the same flexibility and freedom of a free-weight type movement while benefiting from the features of a strength training machine.

### Basic exercises to engage your core and improve balance.

Stand with both feet on the ground and close your eyes. Next, open your eyes, but lift one foot. For more of a challenge, try closing your eyes and balancing on one foot.

To incorporate the toys found in your health club, try sitting on a Physio-ball in place of a chair. When you feel comfortable, lift one foot off of the ground for a few seconds. After you regain balance with both feet, lift the other foot.

Another exercise is to stand on balance discs, one for each foot. In each of these exercises, you may feel wobbly and unbalanced but you are training your muscles to work together to stabilize your body.

For a more advanced exercise, use a Bosu Ball, which is half of a Physio-ball mounted to a flat circular platform. First, stand on the ball side of the Bosu Ball, then advance by flipping the Bosu Ball over and stand on the platform side with the ball side touching the ground.

For the ultimate challenge, try bending your knees to a squatting position and return to a standing position. Once you feel more comfortable using this type of apparatus, use them as a replacement for the tradi-



tional exercise bench or seat and perform your normal exercises. You will be forced to incorporate the entire range of muscles of your torso for stabilization and balance.

Crunches are popular exercises to help strengthen the abdominal muscles. For a new twist on crunches, try performing traditional crunches using the Physio-ball. Sit on the ball, walk your feet forward and keep your feet at least hip-width apart on the ground. The wider your feet are placed, the more stability you are going to have. Slowly lay back on the ball making the surface area from your head to your knees flat like a tabletop. Cross your arms over your chest with one hand on each shoulder. Crunch up to a sitting position, peeling yourself off the ball one vertebrae at a time until you are upright. You can control the intensity of the crunch with the placement of the ball. The further the ball is down toward your lower back and hips, the more challenging the exercise, as you engage your abdominals to support your body.

Improving core strength retrains the body to function in a more efficient way, helping to improve quality of life by making once routine activities again seamless so you may focus on your other interests and hobbies.

*Lauren Bunney is a Fitness Director and a personal trainer for Lifebridge Health and Fitness Center. She is also a runner and member of the national ski patrol.*



## Surrender to the Peace

Breathing in the Present

**M**iss the mark. What is it? Proper breathing—one of the most powerful tools we have for improving our physical and mental health, says Miriam Ratner, MSW, LICSW, psychosocial oncology specialist at the Washington Cancer Institute at Washington Hospital Center.

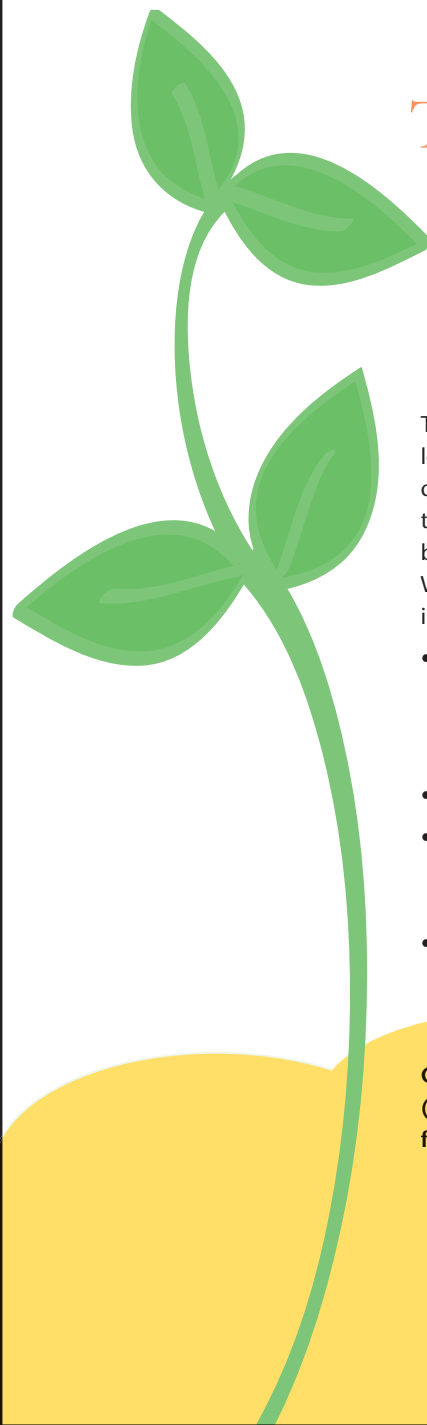
“Studies have shown that rhythmic breathing helps people relax, reduces our heart rate and blood pressure and improves digestion and insomnia,” says Ratner. “It’s so simple, everyone can learn to do it. Actually, we can re-learn. As babies, we breathe properly using our bellies. But as we get older and become more stressed, we take short, quick breaths. To feel the tension leave your body, take deep breaths using your abdomen, fill your lungs slowly but completely, and then exhale, also slowly.”

Ratner has created a wallet card with

five simple steps to help cancer survivors learn to “surrender to the peace” of breathing properly, but the information can be used by anyone interested in better health. Her card is based on the research of Harvard Medical School graduate Andrew Weil, MD, founder and director of the University of Arizona’s Integrative Medicine Program. Over the past 10 years, Ratner has followed Weil’s progress in

bringing complementary medicine into mainstream health care, and she regularly applies what she has learned through her social work role at the Washington Cancer Institute.

*For a free Surrender to the Peace breathing card and/or a Living Well with Cancer kit, call Washington Hospital Center’s DOCTors Line, (202) 877-DOCS (3627).*



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### Active Survivor Network - Calendar of Activities



#### Next Issue:



*Aran Gordon's Challenge*

*Paralympics and Our Misperceptions*

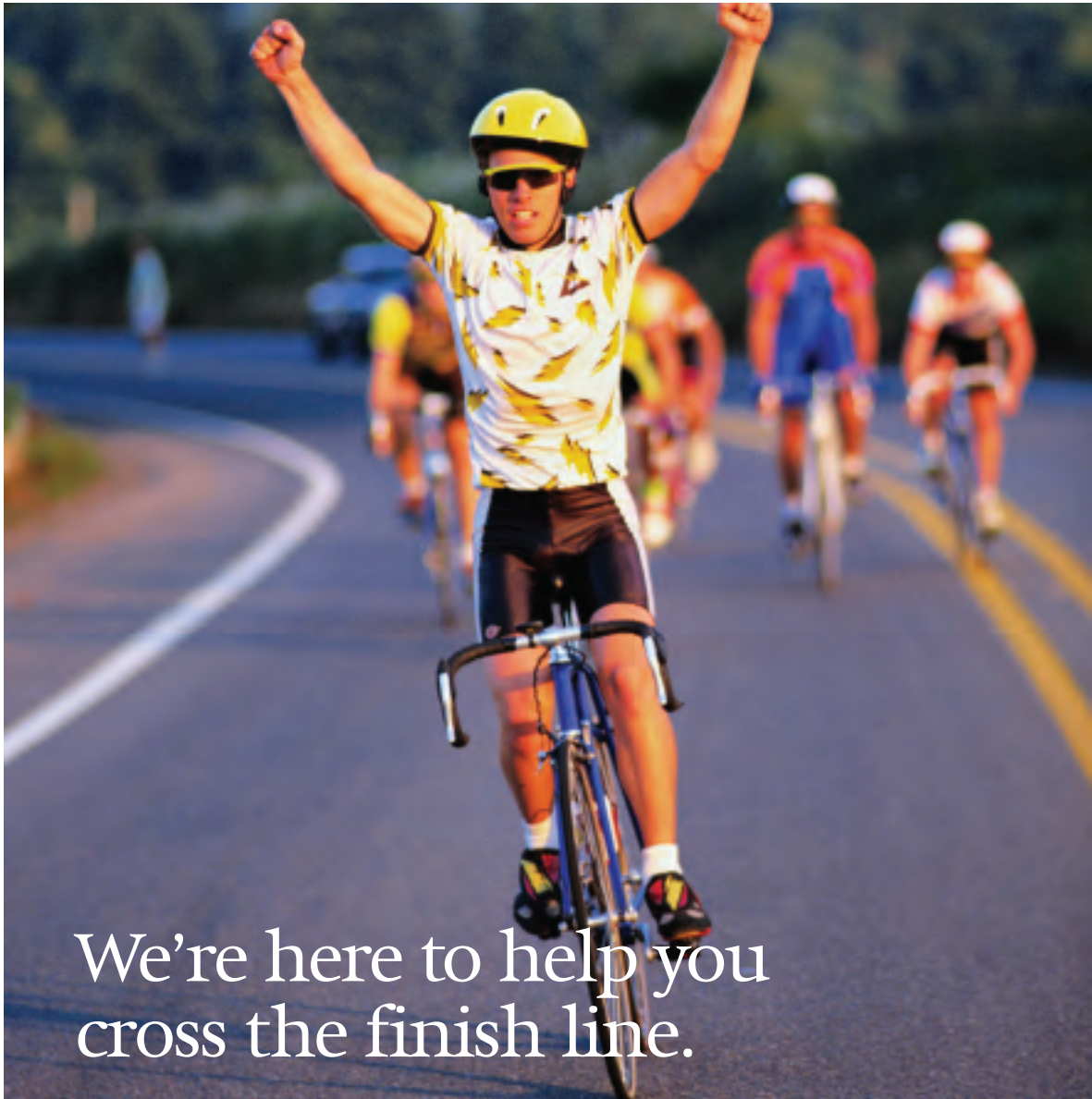
*Mid-Atlantic Survivor Championship Preview*



MARATHON | HALF MARATHON | 5K | 4 PERSON RELAY | KID'S FUN RUN

### Mid-Atlantic Survivor Championships At the Baltimore Running Festival

October 15, 2005  
Baltimore, MD



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