

# *The Most Grateful Patient*

**A monumental comeback raises awareness and inspires thousands**

*By Rolf Benirschke*

The minute my foot connected with the ball, I knew I'd missed. As an NFL kicker, who had kicked thousands of footballs, I knew exactly how it felt to "hit it well or miss it."

Unfortunately, this miss could not have come at a worse time as my team, the San Diego Chargers, was locked in an epic back and forth battle with the Miami Dolphins for the AFC divisional title and the score was tied 24-24 in overtime. Although the game wasn't over, we all know...a kicker rarely gets a second chance in overtime.

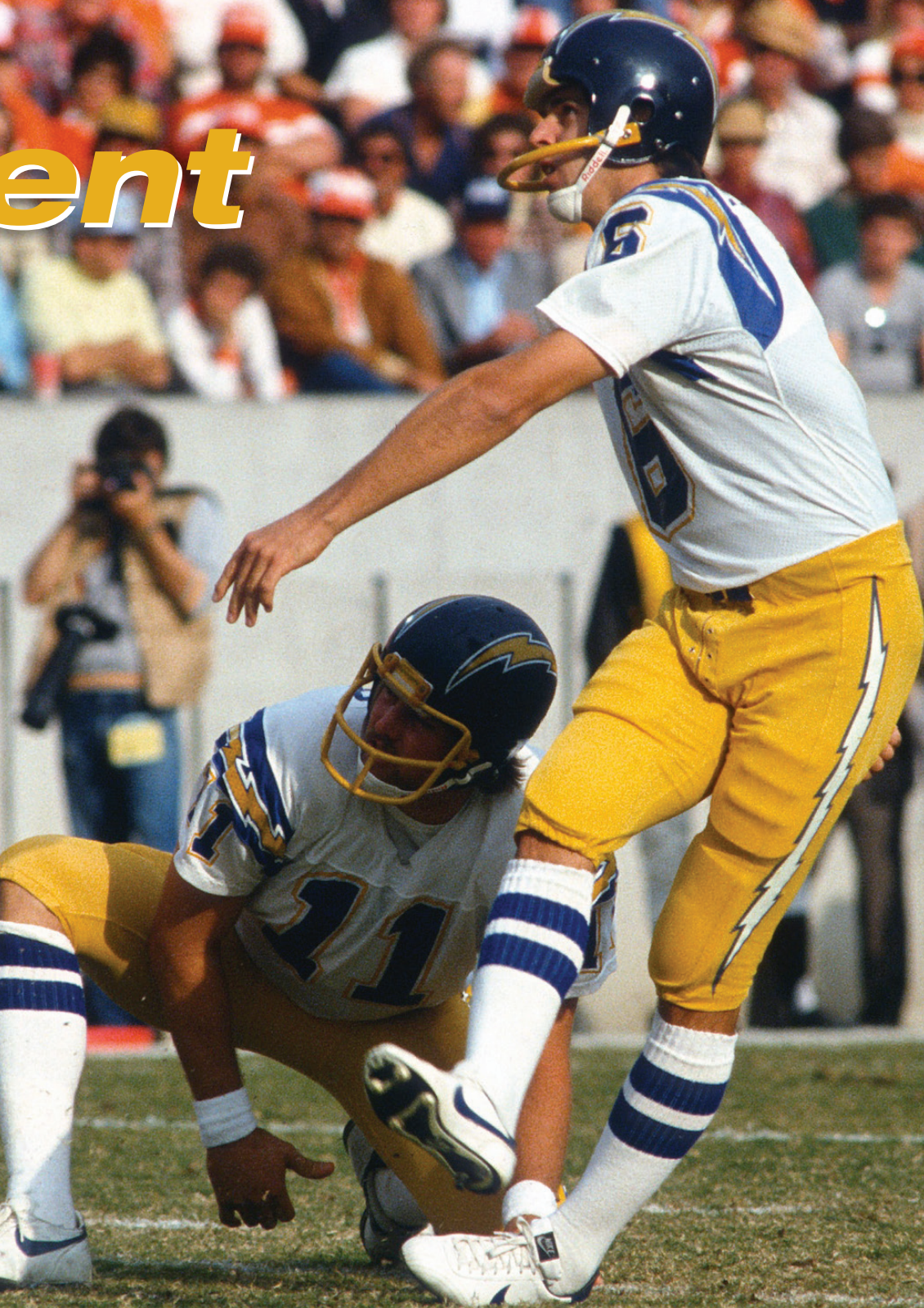
The next few minutes were agonizing as the Dolphins got the ball and marched down the field to set their kicker up for a relatively short game-winning field goal of their own. Amazingly, their kicker missed too! Now with the ball again, Dan Fouts and our offense moved into field goal range and I was given that second chance that hardly ever comes. You can imagine my elation when my kick soared through the uprights.

In many ways, that game was just like my life. Only two years earlier, in my second season of living the dream as an NFL player, I suddenly began experiencing severe stomach cramps and bad diarrhea along with fever. I thought I had the flu but my symptoms worsened and I was forced to see a doctor where I was diagnosed with Crohn's disease and given medication. Although I was feeling miserable, I continued to play.

That season I experienced all the challenges of an IBD patient; doubling over pain, weight loss, fever and the need to know how to find a bathroom...fast. There were also brief respites when the pain was just a dull ache and I learned to live with it. Somehow, I made it through the season, statistically one of the best of my career, and spent the next offseason doing everything I



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*Rolf Benirschke playing  
against Tampa Bay in 1981*

could to regain my health.

I entered my third season still struggling, but the Chargers were pre-season favorites to go deep into the playoffs, and I desperately wanted to be on the team. Things started off well when I kicked four field goals in our opening game but, while everyone else celebrated afterwards, I found myself sitting in front of my locker fighting back tears from the excruciating pain. I was scared about what was happening to me, scared I might let the team down and scared the doctor might make me stop playing. And I simply did not know how I would survive 15 more games.

The end came unexpectedly three weeks later as we flew home after playing the New England Patriots. I collapsed on the team plane and “woke up” with teammates putting wet compresses on my head trying to cool my raging fever. When the plane finally landed, I was rushed to the hospital where doctors determined my colon needed to be removed immediately. There were complications, so I was forced to undergo a second emergency surgery six days later. I awoke from that operation, 65 pounds below my playing weight, with two stomas – a functioning ileostomy and a mucous fistula colostomy, and the physicians telling my parents they weren’t sure I would survive the night.

Looking back at that incredibly difficult time, I know I received extraordinary medical care for five weeks in the ICU, but I am also convinced the Lord stepped in and saved my life. When I was finally released from the hospital after nearly two months, I was a shell of who I had been and was bitter and discouraged. Every time I looked in the mirror, I asked the question every ostomy patient asks, “Why me?” From my perspective, *everything* I enjoyed about life seemed to have been taken from me.

My abdominal incision was being held together



*Rolf's recovery began with the kind and caring nurses at University of California San Diego Medical Center.*

*Rolf receives a lifetime achievement award from UOAA President Susan Burns in 2017 for his three decades of inspiring the ostomy community.*



by piano wires and was so tender I couldn't even get out of bed by myself. I shuffled around the house, barely able to walk unassisted, hoping no one would come to visit. I was angry, scared, alone and embarrassed.

As the days wore on, and reality started to sink in, I did a lot of reading and self-reflection. I began to accept my situation and slowly moved from asking; “why me” to asking, “what now?” With the help of my parents and a few very close friends, I began to activate my old athletic mindset. I knew the importance of goal setting and began to set small achievable goals for myself like walking to the mailbox and back every day. Then two mailboxes. And then three, and eventually being able to shuffle to the end of the street.

And while I desperately wanted to battle back privately and out of the public eye, as a professional athlete I found I simply didn't have that luxury. I had gone to high school in San Diego, our team was beloved by the community, and they felt I was one of “their own” so they were determined to come alongside me in my recovery. I received hundreds of letters of encouragement, flowers, and messages from dozens of churches that were praying for me. It was overwhelming, and even as I write this my eyes are welling up with tears of gratefulness for the many kindnesses shown to me by total strangers.

A local radio station even initiated an impromptu blood drive to replace the 80 units I had needed, and

hundreds of people were willing to wait 3-4 hours just to donate blood! That blood drive became an annual event and the largest single day blood collection in the country every year for the next 35 years and even made its way into the Guinness Book of World Records!

Because I was still under contract with the Chargers, they allowed me to recuperate at the team facility under the watchful eyes of the trainers. At the time, there was never any thought of me playing football again; that was absolutely preposterous and unimaginable. I was just trying to recover and figure out what to do next with my life. Phil Tyne, the team's strength coach, took a special interest in me. I was in pathetic shape when he first started working with me; weighing just 125 pounds, hardly able to lift a 2 lb. dumbbell or walk the length of the field. I clearly had a long way to go to get healthy again, but Phil was undaunted.

Over the next six months, I regained the 65 pounds I had lost. My walking turned into jogging, then running up and down the stadium steps and sprinting on the field. By June I weighed 180 pounds, was feeling strong and began to wonder if I might be able to kick again. I remember asking Phil, "Do you think it is possible I might be able to kick again with my pouches?" He stared at me incredulously and said, "Of course you can kick again! What do you think we have been doing all this training for?"

Phil took me immediately to the practice field where I began drilling kick after kick until I proved to myself that, I could do this again and that my ostomy pouches would stay on. I next met with the team owner, the coaching staff, and the medical staff. And then I went to work to earn my job back. Miraculously, I found myself on the roster for the opening game just eight months after leaving the hospital!

I played four seasons with a traditional ileostomy that

required a pouching system. I was an early candidate for a Koch Pouch that is an internal reservoir made of small bowel that is emptied by inserting a catheter through a small, flush stoma. It is known as a continent ileostomy or internal pouch. That is what I live with today.

The media was very interested in my recovery and I was interviewed by writers and reporters in nearly every city we played in that season. Amazingly, every week after any type of interview, my locker would be filled with letters from patients who were desperate for information and hope. And almost all the letters began the same, "You're the first person I have heard of who has an ostomy. How were you able to play football, and can you give me some advice on how I can return to school, go to work, travel, etc.?"

I learned there are more than three million people in the country who live with Crohn's Disease or ulcerative colitis and tens of thousands who face ostomy surgery every year—but nobody was talking about it. Reading those letters was humbling and inspiring and I began to understand the enormity of the opportunity I had been given. The more patients I spoke to the more I realized that I needed to do something to help others understand that there was life after ostomy surgery... an abundant, fulfilling, and happy life.

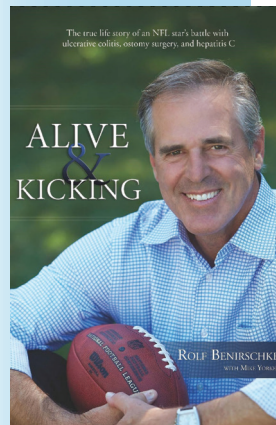
I began to collect and share stories of courageous ostomates who were police officers, firefighters, marathon runners, triathletes, mountain climbers, beauty queens and so many others who refused to accept the parameters of the "restrictive lifestyle box" we ostomy patients thought we were relegated to. WOC nurses, who often believe in us before we believe in ourselves, began to share these stories with their patients. For the last 35 years it has been humbling to work alongside those heroic nurses and encourage thousands of patients

*continued on page 78*

## Journeys of Inspiration

Every ostomy operation is the beginning of three journeys for both the patient and their family. The first is the physical journey of recovery. The second is the emotional/social journey of figuring out how to live your ideal life while wearing a pouch. The mechanical journey is where you learn how your new plumbing works, which system is right for you and where to get your products. While these three journeys can be overwhelming, I've found the absolute best way to get started is by hearing the stories of HOPE from those who have journeyed before you.

Beginning this summer, I'm excited to share inspiring stories in each issue of *The Phoenix* and I would love to have your help. Whether you are a school teacher or an FBI agent, an athlete, or a new mom, every story is encouraging and inspiring to me and will be to our readers who need to hear from you! Please take a moment and visit [www.gratefulostomate.org](http://www.gratefulostomate.org) where I've made it quick and easy for you to share your story. (If we feature your story, I will be happy to send you an autographed copy of my book, *Alive & Kicking*) Thanks for being an inspiration to all of us!



## Wondering what to do with unused ostomy supplies?



**Friends of Ostomates Worldwide-USA** is a non-profit 501(c)(3) volunteer organization which collects new ostomy supplies from US individuals and groups. FOW-USA donates the supplies to needy ostomates in developing countries around the world.

Please send your new supplies to:

FOW-USA  
4018 Bishop Lane  
Louisville, KY 40218-4539

Shipping cost and value of supplies may be tax-deductible.



For more information visit us at [www.fowusa.org](http://www.fowusa.org), call us at 502-909-6669 or email us at [info@fowusa.org](mailto:info@fowusa.org).

## Grateful Patient from page 57

to destigmatize this life-saving surgery.

After I retired from football, I explored different career options, including a brief stint as the host on Wheel of Fortune, but my heart for patients kept calling me back. I've written three books; *Alive & Kicking*, my autobiography, *Great Comebacks from Ostomy Surgery*, and *Embracing Life*, which feature inspirational stories of people who have survived and thrived following their ostomy surgery. And nine years ago, I founded Legacy Health Strategies to help medical device and pharmaceutical companies better engage with their patients.

In 2017 I launched the Grateful Patient Project ([www.gratefulpatient.org](http://www.gratefulpatient.org)) and created National Grateful Patient Day which is celebrated every September 7, the day I returned to play after my illness. I also created The Grateful Ostomate ([www.gratefulostomate.org](http://www.gratefulostomate.org)), a place to collect stories and provide information to help every ostomate and their family members embrace the journey that is ahead of them – not filled with fear and anger and despair, but with courage and hope.

I consider myself the most grateful patient you will ever meet and wake up every morning excited about the work I get to do on behalf of patients. The days that bring me the most joy are those when I get to personally connect with an ostomy patient, listen to their story and help encourage them in their journey. 🙏

## Know Your Pouching System (Appliance) Checklist

Patient Name/Address: \_\_\_\_\_  
 Patient Date of Birth: \_\_\_\_\_ Supplier Contact Information: \_\_\_\_\_  
 Allergy Alert: \_\_\_\_\_ Supplier Order #: \_\_\_\_\_

### Pouching System:

- ☐ One-Piece  
☐ Two-Piece

### Stoma Information:

Size: \_\_\_\_\_

### Ostomy Type:

- ☐ Colostomy  
☐ Ileostomy  
☐ Urostomy  
☐ Other: \_\_\_\_\_

### Brand Manufacturer:

- ☐ Coloplast  
☐ Convatec  
☐ Cymed/  
 Microskin  
☐ Hollister  
☐ Marlen  
☐ Nu-Hope  
☐ Other: \_\_\_\_\_

### Pouch:

Product # \_\_\_\_\_

Size: \_\_\_\_\_

Quantity: \_\_\_\_\_

### Pouch Features:

#### Color:

- ☐ Transparent  
☐ Opaque

### Closure/Outlet:

- ☐ Drainable (velcro or clip)  
☐ Closed-end  
☐ Tap Bottom

### Gas Management:

- ☐ Integrated Filter  
☐ No Filter

### Wafer/Barrier/Flange:

Product # \_\_\_\_\_

Quantity: \_\_\_\_\_

- ☐ Pre-cut  
 Size: \_\_\_\_\_

- ☐ Cut-to-fit  
 Size: \_\_\_\_\_

- ☐ Moldable  
 Size: \_\_\_\_\_

- ☐ Flat  
☐ Convex:  
 \_\_\_\_\_ Soft/Flexible  
 \_\_\_\_\_ Light  
 \_\_\_\_\_ Deep

### Two-Piece:

- ☐ Adhesive Coupling  
☐ Mechanical Coupling

### Accessory Products:

- ☐ Skin Barrier Seals/Rings  
☐ Adhesive Remover  
 Wipes or Spray  
☐ Barrier Wipes or Spray  
☐ Barrier Strips  
☐ Deodorizer  
☐ Paste (Tube or Strip)  
☐ Tape  
☐ Powder  
☐ Support Belt  
☐ Overnight Drainage Bag  
☐ Overnight High Output  
 Pouch  
☐ Irrigation Supplies  
☐ Other: \_\_\_\_\_

**Advocates for a Positive Change**

[www.ostomy.org](http://www.ostomy.org) 1.800.826.0826

