

Post Magazine

Live Discussion with Post Magazine writers

Tom Dunkel and Pat Rummerfield Special to The Washington Post and International Center for Spinal Cord Injury Monday, January 28, 2008; 12:00 PM

When Pat Rummerfield was paralyzed from the neck down in a car crash decades ago, the prognosis was bleak. But with luck and incredible willpower, he started to walk again. And then to run, and to bike, and to swim -- all with no feeling from his knees down. Doctors are hoping they can help other quadriplegics and paraplegics reach the same goal.

Possibilities for the Impossible

Tom Dunkel, whose story about Rummerfield ran in this week's issue of Washington Post Magazine, was online Monday, Jan. 28, at Noon ET to field questions and comments. Joining him will be the medical marvel himself, Pat Rummerfield. A transcript follows.

Tom Dunkel is a freelance writer based in Baltimore. Pat Rummerfield is a patient liaison at Kennedy Krieger Institute's International Center for Spinal Cord Injury in Baltimore.

Tom Dunkel: This is Tom Dunkel. I wrote the "Walking Miracle" story. With me is Pat Rummerfield, the "Walking Miracle" himself. Thank you for joining us today.

We'll answer as many questions as possible in the next hour, with most of those questions presumably being directed toward Pat. So...here we go:

Pat Rummerfield:

1. Thank you for being here today and allowing me the opportunity to chat with all of you. I look forward to answering as many questions as possible. For those of you who post questions we are unable to get to, please contact us at Rummerfield@Kennedykrieger.org

Arkansas: It was an honor for Matt to be a small part of this awesome story of recovery. Your determination and work ethics have inspired Matt to work even harder to achieve his goals. Thanks for being here for him and providing the encouragement that we all needed after this devastating injury. Your life's journey has shown that nothing is impossible if you work hard and never give up hope. We love you!

Pat Rummerfield: Thank you, Matt is a great man with a bright future. Know that your passion and commitment to recovery drives me to continue my efforts. I am inspired by you, Matt and particularly inspired by individuals such as Josh Basile, Eric Westacott, MR Pattison, Elliott Farmer, Jyl Waters, Sam Schmidt, Ricky James, Craig Andreas, Vicki Rosellini, among the many others who I may have unintentionally left out, who have devoted their time to helping and educating others. It's largely through their efforts and others like them that the SCI world is a better place in which to live.

Grants Pass, Ore.: Hey, thanks for making yourself available. My question is this:

My husband is 32, C5/6 brown sequard. Very Incomplete, 1 1/2 years post. Can walk with a walker about 200 feet. We can not afford any PT, so I help him as much as I can with working out. He is reading this right now. What would you say to encourage him? How important is exercise?

Pat Rummerfield: Supportive individuals like yourself make things possible for others. Congratulations to your husband on his accomplishment of 200 ft. Lets turn that 200 ft into 1 mile. Exercise is everything. Like green behavior will create a cleaner, healthier environment, exercise is the foundation for a healthier body. From a minimum of fewer infections and greater cardio capability to a maximum of ambulating, stronger muscles move us all toward achieving these goals. When a cure comes, your body will be better prepared. I started my rehab with a \$5 garage sale item and the help of some friends. Look into various home rehab programs; if you can't find them email me at Rummerfield@kennedykrieger.org.

Columbus, Ohio: First, I would just like to say your story is an amazing testament to the inner strength and will of man. The likes of which I have rarely seen. I am a student in molecular biology at Ohio State University and am fascinated with the way the human body works and responds to accidental events in the environment. These events are termed "Evolutionary Triggers" in that they usually cause any organism that survives them to initiate unusual repair and adaption mechanisms. My question regards dietary patterns over the course of your recovery. I am wondering whether there is one food or food group that you have always heavily consumed and what kind of supplements or vitamins you have taken over the course of your rehab? I ask this because cell cycle (and thus cell regeneration) is dependent on key chemical substances that usually must be ingested to be present at critical threshold levels in the body. Thanks for the time and consideration. And God be with you.

Pat Rummerfield: Thank you for your kind words regarding the story. To answer your question, quads and Para's have different needs than able-bodied individuals. Currently I'm working with a lab that is working on specific supplements for quads and paras. We've been studying this area for the past 6 years. Additionally, when I compete, the supplements I require need to be adapted to address the various needs of my body in that state. You bring up an excellent point, and soon I will be posting my regime on my web site. WWW.Rummerfield.com.

Greenbelt, Md.: Is there any way that activity-based therapy with electrical stimulation could adversely affect an SCI patient?

Tom Dunkel: My understanding is that, properly monitored, there's nothing but upside potential to ABT. In fact, Dr. McDonald makes a point of noting it's the ONLY way quadriplegics can get a cardiovascular workout.

Pat Rummerfield:

In my personal opinion, over 35 years of experience, I have not experienced any negative feedback regarding activity based restorative therapy.

Baltimore, Md.: I read your Washington Post article on Medical Marvels and felt the need to write for advice. One of my closest friends was in a motorcycle accident in May of 2006, and is a quadriplegic as a result of the accident. Unfortunately, my friend did not have health insurance at the time of the accident and has suffered through very poor care. He was in the Univ. of Maryland Shock Trauma for six weeks before they moved him to Keaton in Baltimore where he received below average treatment and now he is stuck at the University Specialty Hospital in Baltimore City, a place where they do not give him the necessary rehabilitation. One of the main concerns with my friend is that he is in constant, severe pain that he loses all motivation for therapy. He has lost all desire for rehab because of this pain. Family and

friends have tried to help him get through the pain, but we all can't even imagine what he must be going through.

His family and I are looking for ways to get him out of this facility and into a place where they may take him for better rehab, clinical studies, etc. He is basically lying in a bed, taking pain killers, with nobody to help him get better. Can you provide me with suggestions to our dilemma as the health insurance issue seems to keep putting us at a road block?

washingtonpost.com: Medical Marvel (The Washington Post Magazine, Jan. 27)

Pat Rummerfield: Please email me at Rummerfield@kennedykrieger.org

Owings, Md.: My uncle was recently injured in a car accident and is now paralyzed from the chest down, he broke his neck at the C6 and C7. He is now in rehab at the National rehab center in Washington, D.C. I was wondering where your injury was located and what therapy seemed to work best for you as far as getting movement back in your hands?

Pat Rummerfield: My injury was located at C3, C4, C5 , C6. The magazine shows a picture of my MRI as well. FES worked best in conjunction with OT.

San Francisco, Calif.: My name is Latonia Jennings and my question is how can I find a medical facility in my area that can help me and my son with this kind of rehab. My son was in a car accident three years ago which left him a quadriplegic, is there some place that can help us.

Pat Rummerfield: Hi Latonia. Please email me and I will try to help. Rummerfield@kennedykrieger.org

Washington, D.C.: I have a 24-year-old son who has been a quadriplegic for the past five years. Amazing attitude and determination. Where in this area can he get therapy in the water, wearing a bag? He receives bowel treatment.

Pat Rummerfield: Congratulations on the attitude and perseverance! Attitude and determination are necessary components in the Iron Will necessary to achieve goals, to be sure. Please email me at Rummerfield@kennedykrieger.org and I will try to help you with this request.

Washington, D.C.: The article mentions Rummerfield's recent grant from DOD to underwrite activity-based therapy research for wounded veterans.

My brother is not a veteran, but could be a great candidate for the type of research McDonald and Rummerfield are doing. He had a C3-4 injury and learned to walk with 2 canes. What's the best way to find out about new studies and whether he's eligible?

Very inspiring story. Thank you!

Pat Rummerfield: Thank you for your kind words. Your brother is fortunate to have such a caring sibling! I may be able to help you with your request, contact me at rummerfield@kennedykrieger.org

Silver Spring, Md.: Pat:

Don't you feel that by contributing time at Dr. McDonald's facility that you're giving the impression that your recovery is somehow connected to his FES technique, when it isn't and that you are endorsing it?

Signed,

A walking quad

Pat Rummerfield: I endorse FES technique. FES technology is state of the art compared to the very basic rehabilitation techniques I used as described in the article. My rehab provided a foundation for the premise of activity based restoration therapy and the FES represents an example of state of the art equipment arising from this premise. I personally have made great gains by utilizing FES and continue using it to this day. My contribution at Dr. McDonald's facility also involves patients, fund raising, and public relations.

Initial clinical research conducted in St. Louis is currently being written for publication. It found that 69% of patients responded to activity-based advanced restorative therapies, including increased muscle mass and muscle strength, and notable gains in motor and sensory function.

Greenbelt, Md.: Does handedness play a factor in motor recovery?

Pat Rummerfield: Sometimes it can make certain rehab efforts more challenging, but there is no evidence that I know of that it inhibits motor recovery.

Washington, D.C.: You have such an amazing ability to pick yourself up and keep going again. Any words of advice for a teenager -- When you feel overwhelmed or hopeless, is there something you do or something you say to yourself that helps get you going again?

Pat Rummerfield: I picture myself in the place I want to be, and visualize every aspect of that goal achievement. Much like the iron man competition, but for smaller goals as well. Success takes and Iron Will and we all have it in us to develop that necessary drive to achieve beyond our current situation. The journey alone makes you stronger. I'm working on a book that will soon be published, and hopefully the message will inspire others on an ongoing basis. Release will be announced on www.Rummerfield.com

Greenbelt, Md.: Is long-term therapy at Kennedy Krieger available to patients with uncooperative, little, or no, insurance?

Pat Rummerfield: As the article stated, I am only one member of a great team of health care professionals employed at the International Spinal Cord Center at Kennedy Krieger Institute who help guide patients through the morass of insurance red tape on a routine basis. We are dedicated to maximizing every available resource for our patients, as well as for potential patients. Please contact us and we will help wherever possible.

Rockville, Md.: Perhaps one can move limbs without feedback. But I also note the girl in Australia that changed her blood type and body chemistry to accept a liver.

Most medical research discredits "anecdotal results" in favor of statistical studies. My take is that a casual relationship expressed as a hypothesis is worth more than a statistical correlation, since cause and effect are difficult to sort out.

What is your take? Can we learn from individual cases? If so, what is the best way to study and learn?

Tom Dunkel: Yes, we can learn from individual examples of recovery. In fact, at times they can point scientists toward promising avenues of research.

On the other hand, scientists being grounded in the scientific method, are interested in replicable results. I think everyone in the field would like to see a large-scale, double-blind study done of activity based therapy.

A major problem is funding. Given this era of government budget cutting, a number of scientist have told me this is the toughest climate they've ever encountered for landing grants to fund research.

Pat Rummerfield: Disabilities like spinal cord injury are highly variable and extraordinarily complex in nature. Accordingly, individuals with SCI are equally complex, variable, and diverse. Additionally, this population is extraordinarily small, and geographically disparate.

This combination of factors makes a scientifically rigorous, double-blinded study monumental to say the least. Currently, Dr. McDonald is pursuing this exact research, however, as with all good research, it takes time. We must temper our patience.

Initial clinical research conducted in St. Louis is currently being written for publication. It found that 69% of patients responded to activity-based advanced restorative therapies, including increased muscle mass and muscle strength, and notable gains in motor and sensory function.

Washington, D.C.: The FES bikes are too expensive to buy(\$18k). Which therapy clinics have them?
Pat Rummerfield: A list of clinics and facilities, including Kennedy Krieger Institute, that use FES bikes is available from Reeve Paralysis Resource Center Information Specialists. Call 1-800-539-7309.

Gaithersburg, Md.: Pat, I also have numbness from the knees down, just as you have. (Mine is from neuropathy.) I gave up driving two years ago because I couldn't feel the pedals. Yet I read that you drive race cars! Do you also drive on the city streets? How do you drive? Is your car customized? I'll appreciate your answers. And please accept my congratulations on your perseverance and hard work and just plain guts.

Pat Rummerfield: Thank you! I drive on the city street without a customized car. I use no adaptive equipment. I start by looking to make sure my feet are on the pedals, then while watching the road, I monitor the speed by rate of passing objects, sound of the motor and speedometer.

California: Hi Pat,

I was wondering who the other guy being interviewed in the video was? Has he made gains in this therapy program as you did? Thanks a lot!

washingtonpost.com: Video: Possibilities for the Impossible

Pat Rummerfield: Matt Courson did a great job in the video, didn't he? Matt is making great gains and we are very proud of him.

Lorton, Va.: Pat,

How have you been doing? Great article! I read it and brought out the K-Log yearbooks to show my wife all high school buddies mentioned in the article. Let me know when you are in town and maybe we can get together. I am still swingin' my hammer for "relaxation" and can make my carpentry skills available to assist anyone who wants help in modify existing structures to accommodate wheelchair access.

Friend I will remember you!

Jack

Pat Rummerfield: Jack,

Please email me your contact information. Great hearing from you! It's always good to hear from an old friend from Kellogg.

Takoma Park, Md.: My husband is an outstanding PT who believes in 60-minute, one-on-one treatments with his patients rather than 15 minutes, followed by 45 minutes with a PTA or unsupervised on a machine. Insurance companies encourage the second scenario, and he doesn't believe patients get better that way. Can you tell me a bit about the environment at Kennedy Krieger? How involved are the PTs with patients?

Pat Rummerfield: Kennedy Krieger is certainly unique in that our physical and occupational therapists provide one-on-one treatments for 3-4 hour sessions. We feel strongly this is of utmost importance to long-term success.

Pasadena, Calif.: Hi Pat, you have a very inspirational story. I have a question about the therapy program at Kennedy Krieger Institute? Has the guy in the video made gains as you have? Are there other patients at Kennedy Krieger who have also made gains with this therapy program? Thanks!

Pat Rummerfield: There are numerous quadriplegics and paraplegics we and others have worked with that have shown significant recovery. Some are ambulating, some are gaiting in a pool setting, and some are running marathons. No small amount of recovery is to be underestimated. Through our efforts at Kennedy Krieger some people no longer rely on machines to breathe, can feed themselves and brush their teeth, maneuver the world in a manual wheelchair rather than an electric one, or hug their loved

ones. Although the article did not explore these areas of functional recovery, our program places great importance on helping achieve important gains such as these.

Owings, Md.: Hey Mr. Pat, its Robby... sorry I got held up with work. How's everything going in here today?

Pat Rummerfield:

Great Robby! Glad to see you're on board with us!

Washington, D.C.: Thank you for sharing your story. You're an inspiration. How important is water-based therapy and exercise for CSI patients?

Pat Rummerfield: Appreciate your kind words. Water therapy is an excellent therapy and exercise is everything. . From a minimum of fewer infections and greater cardio capability to a maximum of ambulating, stronger muscles move us all toward achieving these goals. When a cure comes, your body will be better prepared. I started my rehab with a \$5 garage sale item and the help of some friends. The possibilities for rehab today are boundless. Especially with professionals like PT's and OT's at the International Center for Spinal Cord Injury at KKI stand ready to help.

Pat Rummerfield: To address the question's regarding anecdotal evidence as it relates to SCI patients, Dr. McDonald's program is dedicated to assisting patients in multiple aspects of care. While the thrust of his research is focused on activity-based principles, Dr. McDonald conducts research to identify other therapies that may be applicable as well.

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This combination of factors makes a scientifically rigorous, double-blinded study monumental to say the least. Currently, Dr. McDonald is pursuing this exact research, however, as with all good research, it takes time. We must temper our patience.

Pat Rummerfield: To address the question that some ponder about a person possibly giving false hope, this is my opinion. There's hope, there's no hope and there is nothing in between. Do you know anybody that has no hope but possesses goals? I don't. If you have goals in life, you have hope. And we all have goals. Hope will move you toward goal achievement. The process of hope carries you towards that achievement. Even if the ultimate goal isn't achieved, you will always find yourself closer than before you tried. And that is positive hope, not false hope. You will draw on that to move yourself forward over and over and eventually the goals will become a reality.

We offer the opportunity to increase one's abilities. That is hope. Just because someone doesn't have an identical recovery to mine doesn't mean they haven't progressed and benefited. We aim to maximize each patient's individual potential and functional recovery. That is hope.

Occoquan, Va.: I was so thrilled to read about your recovery! I thought I would one day hear about someone else who experienced recovery from paralysis! I was a c-5/C-6 quad but I have recovered almost completely! I am very dedicated to my health and wellness. I really have to agree with you , Pat, our will and attitude really do affect our bodies. Keep spreading the hope!

Pat Rummerfield: Absolutely! We are on the same page. Congratulations, keep sharing your story.

Washington, D.C.: Tom -- thanks for the splendid article -- I think you were right-on. It's great that you are highlighting such an important topic and it's great seeing the wonderful progress that Pat is making. Mr. S. Not

Tom Dunkel: Mr. Not,
Thanks for the note. I know you do your own form of activity-based therapy. Keep up the good work. On,
on.

Fairfax, Va.: I'm getting visions of Christopher Reeve who struggled with his paralysis. Would the therapy you received have helped him more than what he was receiving? Has the recovery landscape for paraplegics gotten brighter?

Pat Rummerfield: Chris was with Dr. McDonald the last few years of his life and was improving with the therapy, as discussed in the article. The landscape is brightening with novel, cutting edge therapies available today and the International Center for Spinal Cord Injury at KKI. Hope is alive.

Greenbelt, Md.: Are there any treatments or programs SCI patients and their families should avoid, such as possible scams or "miracle-men"?

Tom Dunkel: A note of caution, yes, there are unverifiable therapies out there; shark stem cell implants being done in Mexico, people paying huge sums of money to go to Russia or China for human stem cell implants. Research any therapy well before you pursue it.

Washington, D.C.: Did your therapy include stem cells?

Tom Dunkel: Stem cells played no role in Pat's therapy.

Silver Spring, Md.: Your accomplishments are really miraculous. As a walking quad who had vigorous exercise I can attest to your recovery. My only complaint is that Dr. McDonald uses your self-imposed regime as a testament to his protocol. This to my mind a stretch as his technique of FES has not been well received by the SCI medical community.

Tom Dunkel: I think saying FES "has not been well received" in the medical community may be too strong a statement. Yes, there is some debate. Yes, Dr. McDonald has taken some heat for his belief in the long-term implications of FES therapy and its potential impact on the health-care system.

But, keep in mind, FES itself is relatively new. In fact, they're still working on designing a machine for the upper body.

Pat Rummerfield: FES is well received. FES is the only way to make a muscle contract in a close to normal contraction. Dr. McDonald's approach to the treatment of SCI patients is multivariate, including FES as one component. Many in the SCI community share successes with this therapy on a routine basis.

Manassas, Va.: Hi there my name is Chris. I have been paralyzed now for just about 3 years. I have been wanting to get more active and get out to do more. I just don't know where there is to go for these activities and whom I should contact. Also I don't know what all I am able to do.

Tom Dunkel: Chris, are you speaking of recreational activity? If so, there are groups in most areas of the country that go skiing, play wheelchair rugby and basketball, etc.

Robby Beckman, who is mentioned in the story, takes advantage of those opportunities. In fact, his rugby team practices in Fairfax County. If you email Pat, I'm sure he'll pass the message along to Robby. The Kennedy Krieger physical therapy staff has some ideas as well.

Pat Rummerfield: contact Jody Letrell at 888-923-9222 or info@spinalcordrecovery.org

Alexandria, Va.: Dear Mr. Dunkel,

I enjoyed reading your feature article about Mr. Rummerfield and activity-based therapy in the Washington Post Magazine. I am a C-5-7 quad as the result of a diving accident in 1969. I retired in 2006 after working for 35 years for the federal government and a non-profit organization. I am now 62 years old and have been pushing my manual chair for almost 38 years. My life has been full and my career

rewarding. I am a strong believer in the potential of stem cell research, regeneration research, and I do not doubt the benefits of activity-based therapy.

Your article mentions that activity-based therapy may not be for everyone and that people who feel that way do not come to the center. I strongly agree with Marcie Roth of the NSCIA that there are those in the SCI community who put an unnatural premium on walking. Walking certainly isn't my gold standard - living life to the fullest with the hand I've been dealt is my standard. That means having a job I enjoy, raising a family, participating in sports (like skiing), and among other things, helping to ensure that the civil rights of people with disabilities are enhanced and protected. Getting from point A to point B using a wheelchair is an exercise I don't give much thought to. I have criss-crossed the country in planes, trains, and automobiles more times that I'd like to remember and I don't lose much sleep over the fact that I do it in a wheelchair.

A "walking miracle" is probably just that -- a miracle. I believe, however, there is some danger in being obsessed with such miracles. At the very least, it sends a message of hope that may very well be unattainable despite considerable physical and emotional investment. All of us want to walk again but there comes a point when one must get on with life, never giving up hope, but finding a balance between the limitations of obsession and living a full life.

Thank you for writing the article and I appreciate the appeal of such a story as well as the good work being done by Dr. McDonald in Baltimore and the perseverance of Pat Rummerfield. But please remember that for every "ironman" in the clinic, there are thousands of other ironmen with spinal cord injury who get up every morning at 5 a.m., fight rush hour, work ten-hour days, fight rush hour again, put their kids to bed, and do it all over again the next day. Not terribly exciting, but noteworthy.

Tom Dunkel: Your thoughts are spot on...and not in conflict with what Pat has done.

One of the points Pat and Dr. McDonald make is the importance of retaining HOPE and a positive mind set, to not give in to the negative messages/images so many quads and paraplegics receive from the moment they're injured.

Walking again may not be every person's goal. Indeed, there a doctor at Kennedy Krieger Institute named S.B. Lee, who became a quad in a gymnastics accident as a teen. He uses a wheelchair. Dr. Lee has said that he's not sure he could have accomplished what he's done - meaning earn his medical degree - if he had opted to focus exclusively on walking again.

One other point: the end goal doesn't have to be walking per se....but, rather, staying as physical active as possible. That's so important to overall health for people with SCI injuries.

Pat Rummerfield: Our heroes in the KKI rehab are terrible exciting to us. It's these individuals who inspire us with their motivation and success as their incremental improvements exponentially improve their quality of life. You hit the nail on the head. Potential is everywhere around us and hope and an IronWill drive us to achieve our dreams. Your life and your attitude are an inspiration to us all.

Tom Dunkel: Time is about up. Thanks for all your terrific questions. Pat will try to privately answer those questions we didn't reply to online. If you have further questions, Pat's email address is "rummerfield@kennedykrieger.org".

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