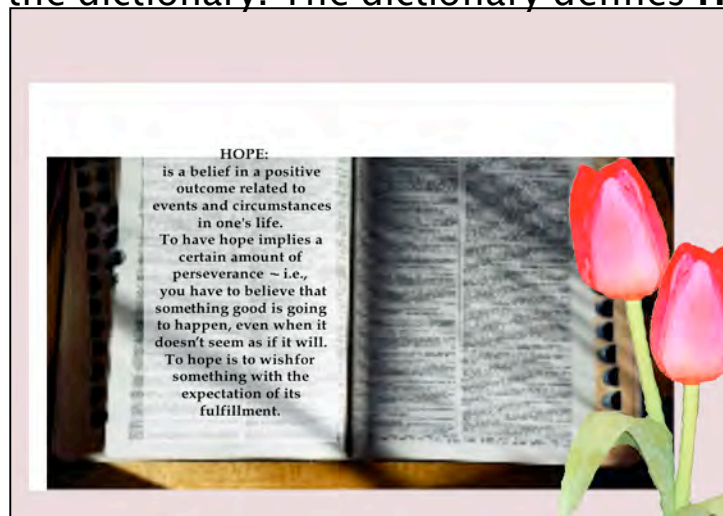


I am delighted to share this presentation with you. I **hope** that you believe in the **importance** of HOPE as much as I do,.. If you don't or aren't sure, then I hope you will by the time we finish.

I think it's essential we all start out on the same page; so let's open the page to the dictionary. The dictionary defines **HOPE** as....



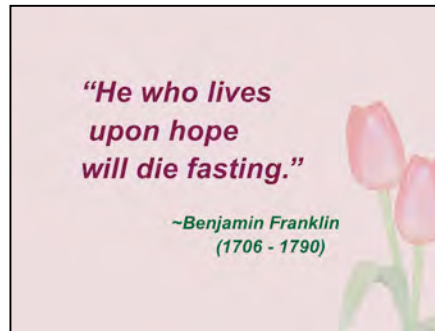
... a belief in a positive outcome related to events and circumstances in your life.

To have hope also requires a certain amount of perseverance — in other words, you have to believe that something good is going to happen, even when it doesn't seem as if it will. To hope is to wish for something with the expectation of its fulfillment.

For example, I **hope** a cure for Parkinson's will be found in my lifetime, but if not, I have high hopes there will be a cure for future generations.

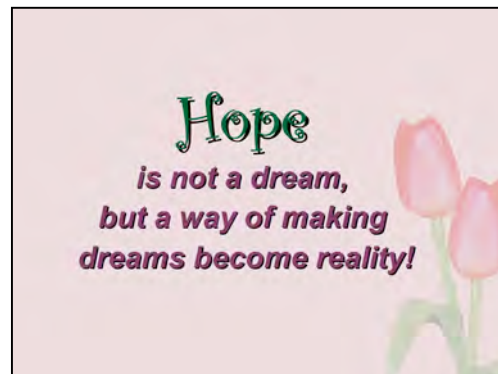
... But as Benjamin Franklin said,  
“He who lives upon hope will die fasting.”

Or to put it another way, you can read a cookbook all day long and starve...you have to take action.



The action I chose to take when I was diagnosed with Parkinson’s disease in 1985 was to **cope**. I realized that living with a “progressive” disease was going to require continuing adjustments and accommodations through the years and that the word “cope” would hold a new importance in my vocabulary.

The decision as to how I would cope was mine, as it is yours. And I decided long ago I would cope with hope. There is no question that life is more difficult for me today than it was 23 years ago but I wouldn’t be surprised if that’s the case for almost everyone.



Hope isn’t a dream, but a way of making dreams become reality...

If you change your thoughts, you can change your world.

So let’s get into some of the ways we can cope, while continuing to hope, by taking action.

## Music: Accentuate the Positive

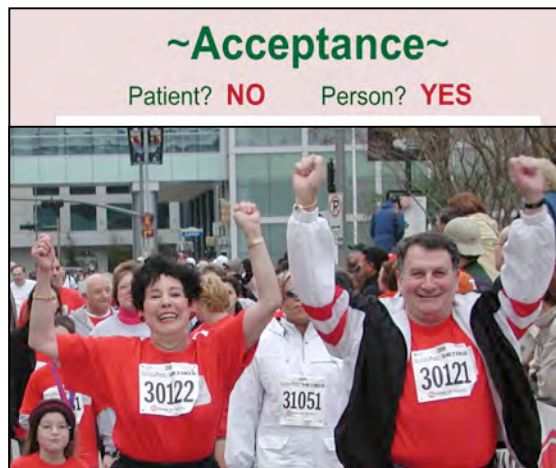


### Let's start by Accentuating the Positive and Eliminating the Negative

If you look at the list you may notice that everything begins with the first letter of the alphabet. Needless to say that was not an accident. The point I wanted to make is that one bullet on the list is just as **important** as the other.

\*\*\*So, the first coping mechanism is to accept that you have Parkinson's.

Being diagnosed with Parkinson's is *similar* to playing a game of cards. You have no control over the hand you are dealt. You just have to play the hand to the best of your ability.



\* I hope you understand that when I say you should Accept Parkinson's, it doesn't mean you need to consider yourself as being "sick." In fact, I get really annoyed when I read or hear someone speak about a Parkinson's "patient".

I don't consider myself a "patient" unless I'm in a doctor's office, which is why I chose this picture.

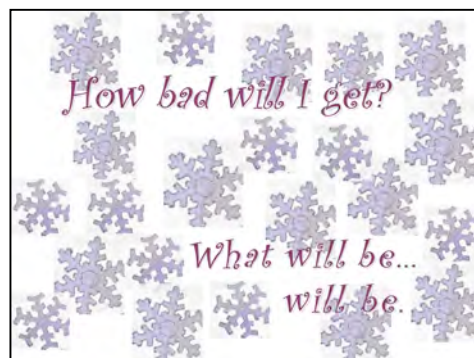
Although you have to admit... unlike having a headache, tremors and dyskinesias can be difficult to hide. It's really easier not to try. So, consider your symptoms an opportunity to educate people, which brings us to the next picture.



In 2005 my 87-year-old father, our children and grandchildren joined Joe and me along with a group of friends and walked the 5K in the Houston Marathon to raise money for the Houston Area Parkinson Society (HAPS). With four generations involved we found ourselves on television, in the newspaper and in magazine articles.

This provided us a perfect opportunity to educate. I explained Parkinson's wasn't contagious.

I let them know that just because they see I can walk one minute doesn't mean I can walk the next; that my wiggling is not because I have to go to the bathroom but from too much medication getting to my brain; and that the beeping they might hear is from a timer that reminds me to take my medication...for which, I am grateful because if there weren't medications available, I wouldn't be able to do the things I do.



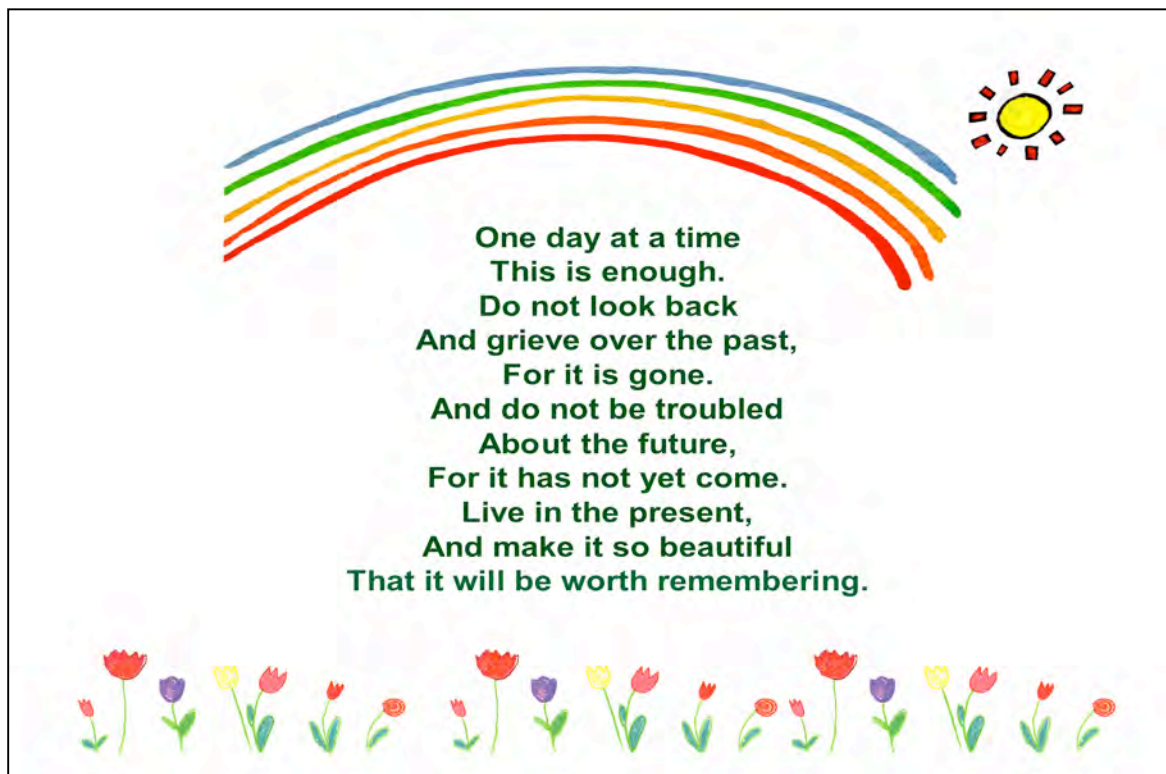
Before we go any further, I'd like to take just a minute to address those of you who may have been recently diagnosed. Before you can comfortably accept the diagnosis, the question "How bad will I get?" will undoubtedly go thru your mind.

I do a lot of research writing the monthly newsletter for HAPS. And the one thing I have discovered over and over again is that I continually find one study that says one thing and another study that totally contradicts the first one.

We all hope for the best, but with all the studies that have attempted to predict the future of how this disease will progress, there are no answers. The course of Parkinson's varies so much from person to person; it is often described as a "snowflake" or "designer" disease.

As a realist, I would be the last person to advise you to stick your head in the sand. You can and should consider the future, as we all should, but tomorrow is going to come regardless, and as the song goes, "what will be, will be."

In fact, I consider the sentiment expressed in this little poem my answer to the question: "how bad will I get."



**Music : Imagine**

I don't want you to think I am suggesting a "don't worry, be happy" attitude; but I think we should look at the bagel, rather than the hole... I believe life should be looked at as an adventure to be lived rather than a problem to be solved.





While I have always felt that Parkinson's is just something I have...like brown eyes, I can understand that Acceptance of a progressive disease may be difficult for some. In fact, I had to re-adjust my thought processes when we took the family to Disney World and I was using the scooter.

I found myself getting off the scooter when pictures were being taken. I stopped getting off the scooter when I realized it would be a far better lesson when the family looked back at the pictures, if they remembered the children taking turns riding on my lap and that Parkinson's didn't stop me from participating in activities involving their lives.

So, my suggestion is that rather than thinking of Parkinson's as a problem... consider it a situation, a challenge, an opportunity to grow, achieve and succeed. You'll be less anxious, less frustrated and less stressed, which will result in fewer symptoms... after all...

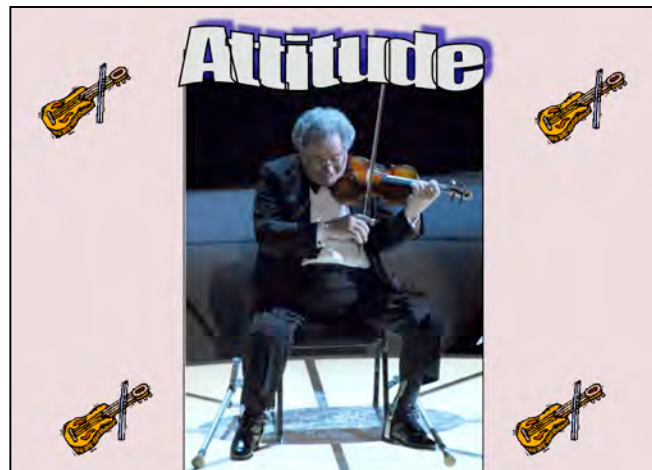


Life is 10% of what happens to you...  
And 90% of how you respond to it!

**Which brings us to attitude...**



\*I can't talk about ATTITUDE without sharing a story with you that you may have already heard and it may not have even actually occurred, but it demonstrates how important ATTITUDE can be in living with a chronic illness.



Music : Itzak Perlman playing

Itzak Perlman, a violinist who was stricken and crippled with polio as a child, was in the middle of a concert performance when one of the strings broke on his violin.

Undeterred, he *closed his eyes* and continued playing with a passion, power and purity that the audience had never heard before.

The audience could see him altering, revising, and recomposing the piece in his head. Most people believe it's impossible to play a symphonic piece with just three strings, so when he finished, applause, screaming and cheering resounded from every corner of the auditorium. When the audience quieted down, Perlman smiled, wiped the sweat from his brow and said:

***"You know, sometimes it is the artist's task to find out how much music you can still make with what you have left."***

Whether this actually happened or not, I would hope there is a lesson to be learned from those words. It's not the problems, trials, tribulations, or roadblocks in life that matter. What matters most is how we handle them and choose to overcome and get through them.



As Winston Churchill said “Attitude is a little thing that makes a **big** difference.”

Let us all hope we are able to learn to make music, at first with all that we have, and then, when that is no longer possible, with what we have left.



You have to know what you want to hope for, so **be aware.**

Take responsibility for your own health care.  
Knowledge is the first positive step you can take toward being in control.



## Become informed

- ✓ Read everything you can find!
- ✓ Visit your library, request to be put on mailing lists for newsletters and medical updates.
- ✓ Use the Internet and attend lectures.
- ✓ Find an understanding doctor with patience, who has knowledge and experience in treating people with Parkinson's.
- ✓ Use your pharmacist as another good resource for information.
- ✓ Participate in a support group for opportunity to share personal advice and support.

\*\*\* Read everything you can find!

\*\*\* Visit your library, request to be put on mailing lists for newsletters and medical updates,

\*\*\* Use the Internet and attend lectures. It will help you understand why symptoms occur so you to know how to describe the problem and what questions to ask and when you see your physician.

\*\*\* Find a doctor who has knowledge and experience in treating people with Parkinson's. Look for one who is interested, patient, understanding, cooperative and willing to take the time to work with you.

\*\*\* Your pharmacist is another good resource for information.

\*\*\* And of course, HAPS has trained professionals on staff to give you support and advice.

## Accentuate the Positive, Eliminate the Negative

- Acceptance
- Attitude
- Awareness
- **Achieve the Achievable**

Next, work to achieve the achievable.

This means you may need to set new and more achievable goals. It's important to learn to pace yourself.



Parkinson's has been described as a "yo-yo" disorder...one hour up, the next down; one day good, the next bad. Just remember that one bad day is only one bad day. It doesn't constitute a trend. Assume tomorrow will be better.

This is important...There have been studies on the "placebo response," that **show your mind can actually help heal your body when bolstered by hope and expectation.** So, altogether now, what do we **NEED?**

And

What have we got?



**Music : We gotta have hope...**



OK, let's not sit around and mope...

Let's accommodate,

And while we're at it...why not do it with flair!



--And put a little pizzazz into it.

\*\*\*For instance, I figured if I am going to take pills every two hours, I might as well enjoy it, so I covered my pill timer with mailing labels printed with pictures of my family.

\*\*\*When I determined I needed a cane, I found one I could fill with jellybeans or gumballs. Not only do I make my grandchildren happy (and lots of grownups too) but also make a fashion statement by switching the colors of candy to match my outfits...

\*\*\*When I needed a walker, I decoupage'd it. \*\*\*Then, when I graduated to a scooter, I chose a red one with the philosophy ...if you've got it, flaunt it!

Then there *are* those times we just have to accommodate to the situation. I was shopping and found myself frozen, unable to move in the middle of a department store so I played bridge on my cell phone until the medication started working enough for me to get to my car.

And since I don't plan to sit around and mope, I've recently made another accommodation and put a lift in my car to take my scooter with me, which will allow me to maintain my freedom a little longer.



Next, I hope you realize how important it is to keep active -- exercise, both physical and mental, is **essential** in maintaining your lifestyle and even determining the course of this disease.

Another quote from Winston Churchill: he said, "It's easy to take a pill, **but to exercise every day, and exercise the brain, is more of a challenge.**"

So are we up for the challenge?



\*\*\* I HOPE so because the latest studies are showing that **exercise slows the progression of Parkinson's as well as possibly encouraging the production of dopamine.** \*\*\* \*I know we all hope that is the case, but we do know for sure that exercise helps preserve muscle tone and function for maintaining mobility, balance, and coordination, and just makes you feel better.

\*\*\* Exercise prevents your muscles from deteriorating, strengthens them, reduces tension and rigidity, and even helps you sleep.

\* **and, by all means, exercise your smile..... TAKE FRANK'S ADVICE**

**Music: Sinatra sings, "When you're smiling"**

\* A smile is an inexpensive way to improve your appearance, so don't forget to exercise it. Our daughter reminded me that, although she was only six years old when my father-in-law passed away, she lovingly remembers his smile—even though a stroke had affected his face before she was born. Smiles can come from within! The Parkinson's "mask" doesn't have to hide the person behind it, nor should you withdraw from life because your appearance has changed or you're unable to do the things you did previously.

\*\*\*\* Make exercise fun! **Music: "Hernando's Hideaway"**

Choose activities that let you play... like, tai chi or golf. And how about HAPS exercise groups—they *always* have fun! You could even try dancing. Dance may appear an unusual choice for those of us that have trouble moving, yet a new study reported that when people with Parkinson's took tango classes, their balance improved. And humming a tune with a beat can help keep you from "freezing" or get you walking again if you do. Life may not be the party we hoped for, but while we're here, we might as well dance, so if **you stumble, make it part of the dance.**

## Keep Active Socially

- ✓ *Don't isolate yourself*
- ✓ *Help someone else*
- ✓ *You may have Parkinson's, but it does not have to have you.*

**It's just as important to keep active socially.**

\*\*\* Don't allow yourself to become isolated. If you participate in support groups, you will meet new people, develop new friendships and help avoid depression. \*

\*\*\* **Instead of focusing on yourself, try helping someone in need.** It will get your mind off of yourself and you'll remember how much you have to be thankful for.

\*\*\* **You may have Parkinson's disease, but it does not have to have you.**

## Accentuate the Positive, Eliminate the Negative

- Acceptance
- Attitude
- Awareness
- Achieve the Achievable
- Accommodate
- Activity- physical and social
- **A sense of humor**

Make sure you maintain a sense of humor.  
And don't forget the rest of Frank's advice....

**Music: Sinatra sings, "When you're laughing" during next slide**

## Keep a sense of humor






## Keep a sense of humor

- ✓ **A laugh a day is more important than an apple in keeping the doctor away.**

*Laughter can be compared to any aerobic exercise. One minute of laughter is equal to 10 minutes on the rowing machine.*

... Dr. William Fry, Stanford University

- ✓ **Learn to laugh at yourself.**
- ✓ **When a chuckle would feel good, go to the closest drug store or card shop and tickle your funny bone  by reading greeting cards.**

**Music: Put on a Happy Face**

\*\*\* A laugh a day is more important than an apple in keeping the doctor away.

\*\*\* In fact a doctor from Stanford University says Laughter is so aerobic that one-minute is equal to 10 minutes on the rowing machine. ....

\*\*\*It's been said that angels can fly, because they take themselves lightly... so **lighten up and laugh at yourself.**

Recently Joe was having such bad back problems he was unable to walk and was using my larger scooter. I was scooting down the hallway at a rather rapid rate when he came out of another room and we collided big time. Although I was concerned I might have given him a whiplash on top of everything, the idea of us playing bumper cars at our age was comical. All we could do was laugh.

\*\*\* But, if collisions aren't your thing, a really easy way to get some good chuckles is to go to the closest drug store or card shop and tickle your funny bone by reading greeting cards



## Music Accentuate the Positive

Maintaining a positive approach to life is a **major** coping tool. I was going to write a report for HAPS newsletter on an in-depth survey that I read.

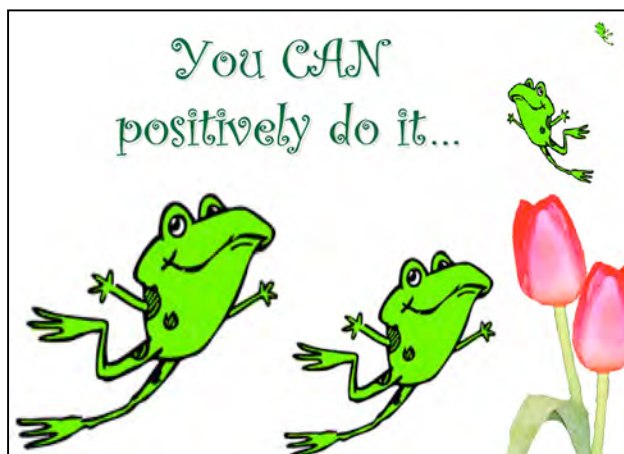
The title was “The Difficult Lives of Patients with Parkinson’s Disease” and it explored the disabling physical, psychological and emotional aspects of the disease, and how it affected the daily lives of people with Parkinson's.

As I read it, I thought of a question that I am frequently asked: “How has Parkinson’s affected my life.” For some reason I always have a problem coming up with a quick answer. I’ve tried to figure out why this should be such a hard question for someone who has lived with Parkinson’s and worked for the Parkinson’s community for 23 years.

Then I realized that people expect to hear a litany of the negative aspects of having Parkinson’s. Because I prefer NOT to dwell upon the things that make my life difficult, but those that make my life full, reading this survey disturbed me.

“The Difficult Lives of Patients with Parkinson’s Disease” concluded with “The results were not reassuring.” If the questions asked in the survey were as negative as the title, I’m not surprised that the results were not reassuring.

I know firsthand that living with Parkinson’s can be a challenge and some days are better than others, but **why not try to figure out ways to make life less difficult, than being told how bad it is.**



### Music Accentuate the Positive

This reminds me of the story of a bunch of tiny frogs that arranged a competition to reach the top of a very high tower. A big crowd had gathered around the tower to see the race and cheer on the contestants.

The race began...but no one in crowd really believed that the tiny frogs would reach the top of the tower. The following statements were heard and repeated over and over again: "Oh, WAY too difficult!!" "They will NEVER make it to the top." Or "There's not a chance that they will succeed. The tower is too high!"

The tiny frogs began collapsing. More of the tiny frogs got tired and gave up...

\*\*\* except for the tiniest frog who wouldn't give up. He continued higher and higher and higher... and after an unbelievable amount of effort, was the only one who reached the top!

All of the other tiny frogs naturally wanted to know how this tiny frog had found the strength to succeed and reach the goal. Anyone have a clue?

*it turned out... That the winner was DEAF!!!!*

*I hope you have already guessed the lessons to be learned behind this story: There ARE times your disability can have a **positive outcome, especially** if you concentrate on accentuating the positive and eliminate the negative, pessimistic people in your life who bring you down.*

### **Hope springs eternal**

*Every morning you wake up you have a choice; you can spend the day in bed recounting the difficulty you have with the parts of your body that no longer work, or you can get out of bed and be thankful for the ones that work.*

### Music: Put on a Happy Face



It's the small daily happenings that can make life spectacular, so accept and appreciate the perks Parkinson's offers:

Forgetting the simple stuff like being able to get a closer parking place, Parkinson's has brought facets to my life that I never could have foreseen—while it has done a lot *to* me, it's done a lot *for* me.



*Without Parkinson's*, I wouldn't be standing before you today giving a talk on hope.

*Without Parkinson's*, I wouldn't write HAPS monthly newsletter, which has given me a personal way to reach out and touch thousands and in return, so many have reached back and touched me.

*Without Parkinson's*, I might never have witnessed the loving compassion from my grandchildren as they remind me to take my pills or take my hand to help me walk.

*Without Parkinson's*, I would have missed the opportunity of meeting some of the most courageous, inspiring, amazing people I know.

*Without Parkinson's*, I would never have had the PASSION or opportunity to fight for and represent the Parkinson community with legislators in Texas and Washington, or help co-found two organizations involved with medical research that give the hope of removing the word "*incurable*" from the description of Parkinson's.



Which brings me to **ADVOCACY**. There is **no way** I could talk about **HOPE** without talking about **ADVOCACY**... which happens to be a cause I am passionate about.

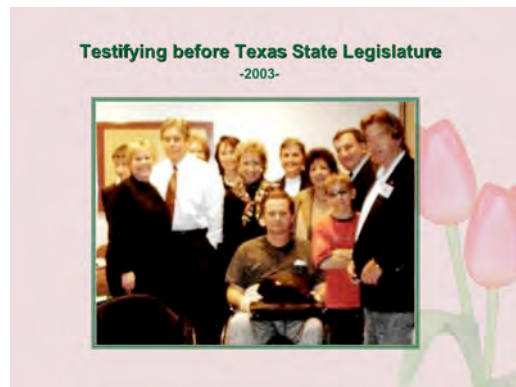
In our capacity as State coordinators for PAN, the Parkinson Action Network which is the *national* voice of advocacy, Joe and I went to Austin in 2003 to testify on behalf of ourselves and other Parkinsonians against a bill that would not only have put scientists in jail for researching certain stem cells in Texas, but if you or I left the state to get treatment elsewhere, when we returned, we would have been subject to a fine of not less than half a million dollars and the possibly of serving 10 years in prison as a felon... as would anyone who went with us, and even the doctor that sent us



Martin Luther King, Jr. once said, ***"Our lives begin to end the day we become silent about things that matter."***

And ***this*** was definitely something that mattered too much for the health and well-being of millions to be silent about!





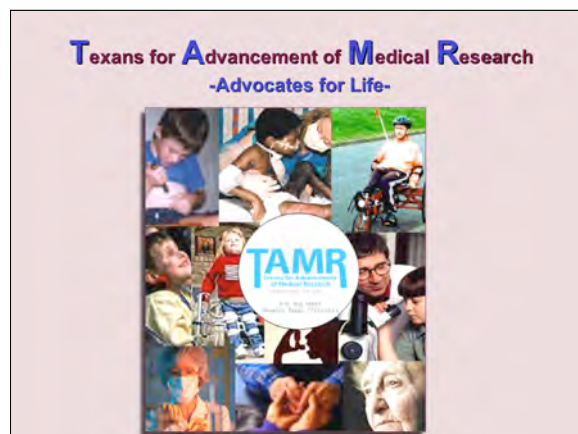
While Joe and I were waiting to testify, we were talking with others who had come for the same reason... some with ill children, siblings, or parents... and some afflicted with devastating diseases and injuries. Few of us had political connections. We didn't have money to spend on communication, public relations, education or legislative advocacy, but the one resource we did have was the passion and determination to want to protect cutting edge research that could one day heal our loved ones and ourselves. To be able to do that, it was obvious we needed to learn more about the legislative process and how it worked, so we listened and leaned ...our heads were spinning, but WE LEARNED...

### Music : Texas side step

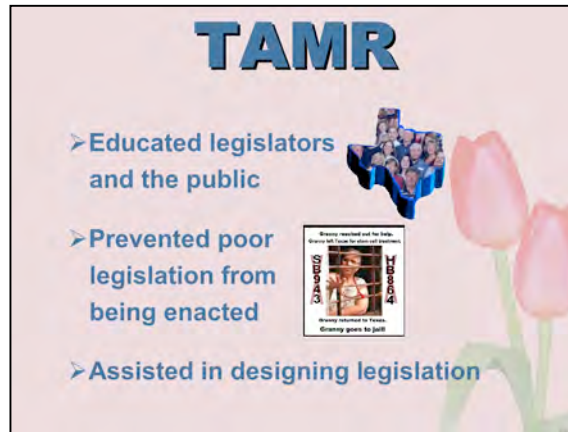
Yes, we learned...so this small group of grassroots advocates bonded together to form Texans for the Advancement of Medical Research or TAMR, with the tag line, Advocates for Life.



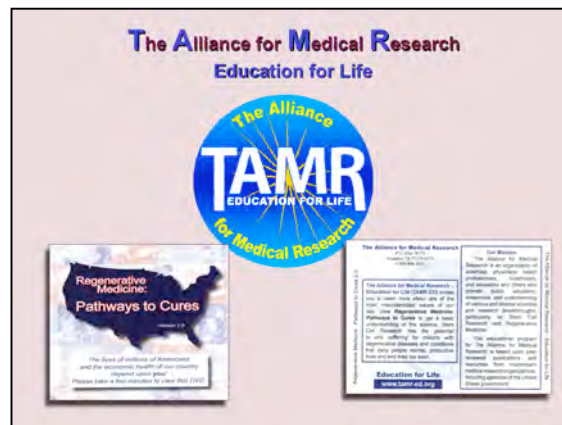
TAMR has now grown into a statewide organization that has become a national model of legislative advocacy and a grassroots organization that serves as a resource to other states.



In retrospect, although it seemed an impossible task to go up against a number of powerful state legislators and several well-established statewide organizations that had the advantage of over 30 years of experience and millions of dollars, ... TAMR prevailed and, incredibly, we won. We kept the bill from being passed.



Now the public was becoming more aware of stem cell research and the average citizen was being asked to support or reject public policy impacting this new field of medicine, even though they might not understand it



So, in 2005, a small group of us decided to establish a national organization, called The Alliance for Medical Research, with the tagline, Education for Life, hence TAMR–Ed, whose purpose is to furnish the public with unbiased, non-partisan education on the science of Regenerative Medicine.

TAMR–Ed produced an award winning, 15-minute DVD entitled Regenerative Medicine: Pathways to Cures that is easily understood.

I am proud to say I played a part in the writing and production of this “stem cell 101” which has also been hand delivered to every legislator in Austin and Washington before critical votes.



While I believe that circumstances may determine our lives, I also believe we shape our lives by what we make of our circumstances. When we were in Washington visiting legislators, a friend told us of her experience with an airport attendant. Being pushed in a wheelchair and barely able to move at the time, Peggy underwent the "pat-down" with dignity, but with difficulty.

As Peggy attempted to gather her things together, the attendant told her "I hope wherever you are going, it's worth it."

**Technology has put the potential to cure or control so many diseases within our grasp. Since we are not scientists or politicians, advocacy is the one thing that we can do to give future generations and ourselves hope.**

There is no question in my mind or Peggy's that IT IS WORTH IT!

I tried explaining how I felt to a young friend who also has Parkinson's. When I suggested he help us in our advocacy efforts, he told me he had only been diagnosed for three years and he could "*handle*" having Parkinson's right now and didn't want to think about the future. I was *speechless*! How can we *not* think about the future? We *must* think about the future! We must "*handle*" it now, so we don't have to handle it later.



That experience was poles apart from a doctor on the left who called me a few years ago and was depressed because he had to give up his practice. After Joe and I talked with him, he proceeded to immerse himself in the stem cell issue.

Like the caterpillar that once thought life was over, he has become a butterfly.

Not only has he become a superb and knowledgeable advocate but he also re-involved himself in the medical field and even set up his own stem cell lab.

The physician, philosopher and theologian, Albert Schweitzer was quoted as saying, “At times, our own light goes out, and is rekindled by a spark from another person.”

Being the spark that lit this fireball is one of the greatest achievements of my life!



**Music : Impossible Dream (plays to the end of the presentation)**

As Michael J Fox has said, “The fight against Parkinson’s is winnable -- and *you* can play a part in the victory”



# Advocate, Advocate, Advocate



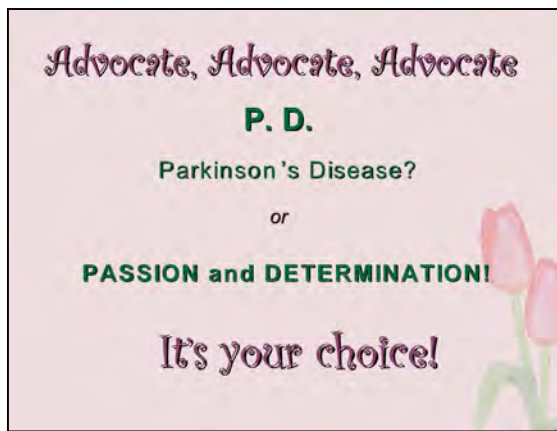
Scientists have told us that Parkinson's is the *most* curable of the neurological diseases and I am more encouraged than ever before that the possibility of a cure may become a reality and Parkinson's can be a thing of the past.

When we went to our first PAN meeting in 1997 there were about 50 people attending and the theme was "Invisible, no more."

At last years Forum, 300 PAN advocates made over 250 visits to legislators up until the time they had to close the offices due to snow and ice. I get chills as I say this, not because of the weather, but because of the dramatic change in Parkinson's awareness and funding for research that has occurred over the past ten years.

Although people with Parkinson's are no longer invisible, there is still opportunity for you to make a difference by being proactive.





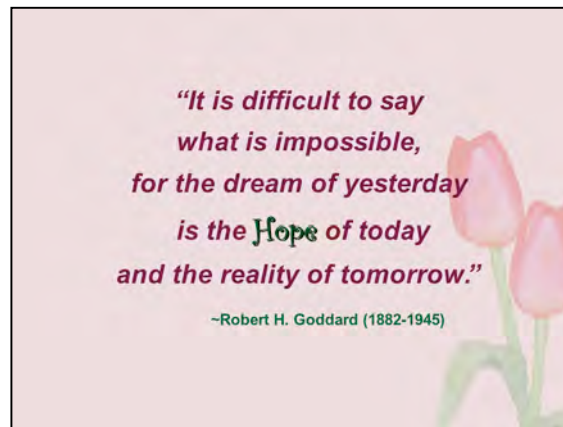
When you say you have P.D., do you want it to stand for  
Parkinson's Disease

OR

Would you rather have it stand for **Passion and Determination?**  
It's your choice!

Passion and Determination have inspired me to do things I would never have otherwise done, improving my quality of life, giving me a sense of growth and accomplishment... and the faith that, **in life, there is a reason for everything.**

Working for the Parkinson's community is what Joe and I do - it's our passion. I hope you will find something that you can become passionate about. It doesn't have to be our cause (although that would be nice) ...it could be gardening, volunteering or even building rockets, like Robert Goddard, who launched the space age with a 10 ft. rocket in his New England cabbage field. Goddard said...



"It is difficult to say what is impossible, for the dream of yesterday is the **hope** of today and the reality of tomorrow."

Life has no certainly...none of us really know what the future holds... but we **can** make the **most** of the present...and there is **always** reason to hope.

I'd like to close with little poem and encourage each of you, to not only keep your hopes high, but join me as an

**Advocate for *LIFE!***

## You are a Work of Art



We are born into the world

Like a blank canvas.

And each person that crosses our path

Takes up the brush, and makes  
his mark upon our surface.

So it is we develop...

But we must realize there comes a day

That we must take up the brush,  
and finish the work.

For only we can determine-if we are to be  
Just another painting or

**A MASTERPIECE.**

# Hope

(not the end ...  
just the beginning)

