

# ***Parkinson's Patients Support Groups, Inc.***

P. O. Box 60188, Sunnyvale, CA 94088 408.542.5610 [www.ppsg.org](http://www.ppsg.org)

**February/March 2011**

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## **Dance for PD at the Parkinson's Institute**

**By *Dance for PD* Facilitator Damara Vita Ganley**

“Nothing will dazzle you like the dreams of your body” – Mary Oliver

This past December the weekly *Dance for PD* class at the *Parkinson's Institute* in Sunnyvale held their first community performance and sharing. It was overflowing with joy and meaningful moments. In essence it was a celebration of what dance truly is and what it offers – expression of the heart.

As a professional modern dancer with the *Joe Goode Performance Group* and *Project Bandaloop*, I have toured the world and danced in many magical places but I do not hesitate when people ask me where my favorite place to dance is. I always answer “with the participants of my *Dance for PD* classes at the *Parkinson's Institute*”. I say this because these classes define for me the purpose and importance of why I have chosen dance as a career – it connects us to ourselves, to our vitality, to our humor, to our community and to the grace and vulnerability of being human.

*Dance for PD* is a program that emerged out of collaboration between the world-renowned New York based modern dance company *The Mark Morris Dance Group* (MMDG) and the *Brooklyn Parkinson Group* (BPG). In the fall of 2001 they started offering free dance classes for people with Parkinson's in New York. BPG's Executive Director Ollie Westheimer approached MMDG with the initial idea for a class. Since 2005, the two organizations have expanded the *Dance for PD*<sup>®</sup> program into more than 40 other communities around the world by engaging participants in Dance

for PD<sup>®</sup> master classes, training teachers through intensive workshops, and by nurturing relationships among organizations so that on-going classes are available to local communities.

The *Dance for PD*<sup>®</sup> program is built on one fundamental premise: professionally-trained dancers are movement experts whose knowledge is useful to persons with PD. Dancers know all about stretching and strengthening muscles, and about balance and rhythm. Dancers know about the power of dance to concentrate mind, body and emotion on movement because they use their thoughts, imagination, eyes, ears and touch to control their bodies every day.

In 2008 I was fortunate to be invited to participate in a teacher training by the founders for *Dance for PD*. Prior to my first teachers training workshop with David Leventhal and John Heginbotham of the *Mark Morris Dance Company*, I had no knowledge of Parkinson's Disease. Taking this workshop was one of the most inspiring moments of my dance career. Although I have danced for much of my life, in that first weekend workshop led by David and John I met people who revealed to me the fundamental reason why I dance.

Choosing a life of dance is challenging, and sometimes in the midst of all that underpaid and overworked flurry and the ever-present grip of financial and personal insecurity we can forget the magic at the heart of what dance is.

Dance is not about achieving perfection. In fact it is about revealing the beauty of our vulnerability. It is opening us to the enrichment of expression and connection. Dance is not a tangible, measurable thing – it is like love, it is like life, it is a mystery that exists between us. The classes that I facilitate

teach this to me every week. They bring me into a deep encounter with dance as a practice of building and renewing community and connectivity.

My *Dance for PD* classes emphasize what I have been calling ‘the virtuosity of experience’. From warm up to choreographed dances or improvisational structures, we move to inhabit our bodies as fully as we can, to dig into those experiences and draw forth expression. Each moment is a discovery of what is possible.

Music is the central inspirational structure but we also use imagery story, text, song and rhythm. We become tangled with joy and also reach out with tenderness. In an hour and a half classes it is possible to feel moved to tears from both laughter and expressions of the heart. As a facilitator I strive to cultivate a classroom culture that is based on trust so that people feel safe to solo from their wheelchair or step into the center of the circle to lead an improvisation. I continue to be in awe and humbled by the participants’ creativity and willingness to be vulnerable and powerful all at once. I learn from them what it means to truly be a dancer in life.

**The *Dance for PD*** at the *Parkinson’s Institute* is held every week on **Tuesdays** from **10:30 – 12pm**. Call in advance to make sure class is taking place that week **408.734.2800**

For more information about *Dance for PD* please visit **[www.danceforparkinsons.org](http://www.danceforparkinsons.org)**

For information about the *weekly Dance for PD* classes at the *Parkinson’s Institute* please email Damara at **[damaravita@yahoo.com](mailto:damaravita@yahoo.com)**

### **PPSG Board Meetings**

You are welcome to drop by our board meetings and share ideas with us! We meet on the **3rd Monday** of the month between **1:00 and 3:00 PM** at the Parkinson’s Institute, at 675 Almanor Avenue, Sunnyvale, CA 94085. To confirm meeting dates and time, please call us at **408.542.5610**. If you are planning to attend, please call Charmaine Eng at 408.723.8116 (dial \*82 before the number).

### **Exercise and Heart Health for PD Wednesday February 16th, 1:30pm - 3:30pm**

This event will feature presentations by staff from The Parkinson's Institute and Clinical Center who will explain why exercise is a cornerstone of Parkinson's care as well as how to keep your heart healthy.

Space is Limited. Please RSVP by February 10th with **Lauren Zachry (408) 542-5636** or **[lzachry@theipi.org](mailto:lzachry@theipi.org)** Event at The Parkinson's Institute and Clinical Center, 675 Almanor Avenue, Sunnyvale, CA 94085.

### **Newly Diagnosed Seminar March 3rd, 2011 1:30 pm - 3:30 pm**

This free seminar is for patients and their care-partners. Our staff will discuss the basics of Parkinson's and have a Q&A session for those diagnosed within the last two years. RSVP by February 25th with **Gloria Goldstein (408) 734-2800** or **[info@theipi.org](mailto:info@theipi.org)** Event at The Parkinson's Institute and Clinical Center, 675 Almanor Avenue, Sunnyvale, CA 94085.

### **Nutritional and therapeutic potential of Spirulina.** Khan Z, Bhadouria P, Bisen PS. **FYI**

Department of Biotechnology, J.C. Bose Institute of Life Sciences, Bundelkhand University, Jhansi 284128, U.P., India.

**Spirulina**, a filamentous cyanobacterium, possesses diverse biological activities and nutritional significance due to high concentration of natural nutrients, having bio-modulatory and immuno-modulatory functions. Different Spirulina preparations influence immune system viz. increase phagocytic activity of macrophages, stimulating the production of antibodies and cytokines, increase accumulation of NK cells into tissue and activation and mobilization of T and B cells. Spirulina have also shown to perform regulatory role on lipid and carbohydrate metabolism by exhibiting glucose and lipid profile correcting activity in experimental animals and in diabetic patients. Preparations have been found to be active against several enveloped viruses including herpes virus, cytomegalovirus, influenza virus and HIV. They are capable to inhibit carcinogenesis due to anti-oxidant properties that protect tissues and also reduce toxicity of liver, kidney and testes.

**PMID: 16248810 [PubMed - indexed for MEDLINE]**

**From PubMed.gov, U.S. National Library of Medicine,  
National Institute of Health ([www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov))**

# An Introduction to Home Health

By Julie Bergman, RN, MSN

In September of 2010, I made the decision to leave the Parkinson's Institute. On my last day, I was crying over my goodbye cake and laughing at the same time as Dr. Brandabur was staring at me saying: "Geez, it's not like we fired you!" It was hard to leave such a loving family but I'm fortunate to still be a part of this family as I embrace my new position as a Care Transition Coordinator at Amedisys Home Health.

Home Health is an exciting, dynamic, and evolving industry that provides a valuable support service to my favorite population of patients: the baby boomers. As the amount of baby boomers multiplies, the in-home care demand of patients will increase. According to Senior Marketplace, "By 2011, 10,000 people will be turning 65 each year and 85% will at some point require some sort of in-home caregiving assistance." Senior Marketplace also projects that "by 2030, 70 million Americans will be over the age of 65" (2010). These figures will certainly place a large demand on our healthcare resources and propose a complex dilemma; how will we care for all of these patients? To complicate matters, how will we care for the chronic illness complications that will persist among this population?

Home Health offers an alternative to the expensive cost of placing patients in nursing homes and board and care homes. Home Health consists of ancillary services that include Skilled Nursing, Physical Therapy, Occupational Therapy, Social Workers, and Speech Therapy. These services are provided in the home at no cost to the Medicare patient.

Beginning in January, a new program called Telehealth will be implemented. Telehealth allows us to monitor the patient in their home and acquire real time vital statistics on the patient.

Amedisys' mission statement is "to provide cost-efficient, quality health care services to the patients entrusted to our care." Amedisys is the first company to roll out their Care Transitions Program, which is the role I was hired to fulfill. This initiative "is designed to reduce unnecessary

hospital readmissions through patient and caregiver health coaching and care coordination which starts in the hospital and continues throughout completion of the patient's home health plan of care" (2010). The idea is to provide more seamless quality care that prevents patients from falling into the proverbial "black hole" after being discharged from the hospital. Home health can reinforce the teaching initiated by the hospital and can continue care that is not hospital-level appropriate care. Reducing hospital stays and hospital readmissions also reduces hospital-associated infections.

Overall, home health offers a tremendous amount of support. The limitations of home health are that it cannot offer 24 hour care, which still leaves a gap for patients who do not have caregiver support or who only have limited support. I encourage everyone reading this to contemplate the future issues we will be faced with and to participate in legislation wherever possible. Adequate health care, in my opinion, should be a basic human right, not a privilege. So how do we make this happen? I encourage everyone to take some personal responsibility to ponder a solution...and while you are at it...pray for peace on earth too. ☺

**Julie Bergman, RN**

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<http://www.amedisys.com/about.htm>

[http://www.seniorcaremarketer.com/seniorcare\\_statistics.htm](http://www.seniorcaremarketer.com/seniorcare_statistics.htm)

## A Note to Readers

**This newsletter is for informational purposes only. Readers are advised to consult a trained medical professional before acting on any of the information in this newsletter.** The fact that a particular treatment, nutrient, herb, or supplement is discussed in this newsletter in connection with any illness or condition does not necessarily mean that it is safe and appropriate for everyone or that the editor or PPSG recommends its use for that illness or any condition.

### Disclaimer

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## **“Parkinson Support Groups: Invisible Threads that Bind”**

**Leonard M. Zunin, MD**

**Facilitator - Napa Support Group (PANC)**

*"We cannot live by ourselves alone.*

*Our lives are connected by a thousand invisible threads."*

Herman Melville

### **Support groups - A time-tested strategy**

In the 1960s, they were revolutionary. In 2011, support groups are a mainstay in a multi-faceted approach to Parkinson's.

Parkinson's support groups promote a focused social interaction in which a small group of people with Parkinson's (and perhaps their caregivers and sometimes their friends), meet regularly with a facilitator. The purpose? To share information, address common problems, improve coping strategies and foster camaraderie.

The very act of listening and sharing offers the opportunity to function more effectively and continue to grow emotionally,

### **Sharing challenges, sharing solutions**

Individuals respond to a Parkinson's diagnosis with a variety of emotions: disbelief, anger, fear, embarrassment, depression, and anxiety among them. Participants come to a support group hoping to improve their lives. Each participant is unique, as is the nature of their disease. Each brings to the table different coping skills and life experiences. They benefit from the group in different ways and at different rates. Watching others cope with similar problems successfully often instills hope.

### **Moving out of the shadow of isolation**

We are social beings with lives characterized by relationships. Much of self-esteem is developed via feedback from others. Some distortions in the way we see ourselves and others are part of the normal pattern of living. Yet these distortions can damage even our most important relationships. The support group provides a forum in which to safely talk about our perceptions.

A common feeling among people with Parkinson's is isolation from others. Many experience great difficulty sustaining interpersonal relationships. They may feel unlikable and unlovable. The support group often provides the first time they feel understood and see similarities to others dealing with Parkinson's. Enormous relief often accompanies the recognition that they are not alone.

Frequently, people with Parkinson's feel that their behavior and responses in the face of the disease, are abnormal. Helping people see that their reactions are a *normal* response to a unanticipated life altering illness, is called normalization. Support groups often provide normalization which can be a powerful healing factor as individuals replace their feelings of separateness with a sense of acceptance and sharing.

### **Gaining knowledge enhances coping**

Most participants leave the group far more knowledgeable about their specific symptoms and challenges than when they entered. This makes them increasingly able to help themselves and others. How is this accomplished? By group sharing and by intermittent presenters and speakers from outside the group, often professionals in specific areas such as voice therapy or current medication options.

When we reach out to others, we reach in to the best in ourselves.

One of the greatest strengths of Parkinson support groups is that they offer members a unique opportunity to help others. Too often those with

### **Tips for the Parkinson's Patient**

**Take a deep breath before you start to speak:** pause between every few words or even between each word.

**Exaggerate your pronunciation of words.** Force your tongue, lips, and jaw to work hard as you speak. Enunciate as if your listener is hard of hearing and needs to read your lips.

**Finish saying the final consonant of a word before starting to say the next word.**

**Express your ideas in short, concise phrases or sentences.**

**Face your listener.**

**Take your time in organizing your thoughts**

**Encourage your family and friends to ask you to speak louder.**

**Talk for yourself.** Don't get into the habit of letting others do all the talking for you.

**Keep in mind that your ability to speak clearly now requires your conscious and deliberate effort and attention.**

Edited from the Summer 1990 issue of The Parkinson Paper. This article was forwarded by Lois McPherson, Leader of the Saratoga Support Group. Thanks, Lois!

## After a Diagnosis of Parkinson's, A Sister Devoted

By ANN FARMER

**New York Times**, December 25, 2010

Agneta Welber has lost track of how many home health aides have come and gone over the past five years. Some lasted long enough to “cash a check and not come back.” Others, she said, “took one look and walked out.”

“Everyone said, ‘My back,’ ” said Ms. Welber, 54, the primary caregiver of her older sister, Esther Welber, 60, who has Parkinson’s disease and uses a wheelchair. Agneta needs the aides to help her lift Esther in and out of her bed, into her wheelchair, onto the toilet and so on.

Esther’s condition, a degenerative neurological disorder, produces muscle rigidity and constant tremors, so she must also be bathed and fed. She needs help with daily home exercises to stem the onslaught of her disorder. And then, there is the help she needs with cooking, cleaning and other chores. Agneta spends most of her time in her sister’s Borough Park, Brooklyn, apartment rather than her own, one block away.

“I don’t have a life,” said Agneta, who is unwavering in her devotion to her sister. Neither is married. Their parent

s were Jews from Hungary, Auschwitz survivors who emigrated to the United States after their families were wiped out during World War II. The two sisters have no other close relatives. Their father died young, at 51; Agneta was 16, Esther 22. For the 11 years before their mother died in 2005, Agneta had been caring for her; their mother had kidney failure among other ailments and was undergoing dialysis before her death.

Esther’s health has declined quickly since she received her diagnosis five years ago. “I’ve been told that I don’t have to do this, that there are other choices,” Agneta said. “But maybe she dies or is abused in a nursing home. I couldn’t live with that.”

Each month, it is a strain to pay the bills. Their combined monthly Social Security income of \$1,724 must cover both of their rents, as well as food, medicine and other living expenses, including

Parkinson's believe they have very little to offer others because they need so much help themselves. Profound feelings of inadequacy may result The process of helping others is a powerful therapeutic tool that greatly enhances feelings of self-worth. In addition, caregivers in the group not only learn about Parkinson's disease, but receive support for their efforts and share coping strategies with each other and with those for whom they are caregivers.

### **Support groups vs. psycho-therapy groups**

A skilled support group facilitator models active listening, gives non-judgmental feedback, and offers positive support. Over time, members often incorporate these behaviors. Facilitators strive to create a safe environment for group interaction and coordinate activities to help provide avenues of involvement for each participant.

The facilitator is typically *not* a professional therapist. Therapy groups often include the issues noted above, but the focus of the group and qualifications and role of the therapist are different. Like support groups, psychotherapy groups aim to increase the individual's sense of their own well-being. However, the therapist uses a range of techniques based on experiential relationship building, dialogue, communication and behavior change. Some Parkinson's patients may find value in participating in both a support group and psychotherapy. However, most people with Parkinson's find great benefit in support groups alone.

### **The mystery of an unimagined life**

No one's life unfolds exactly as they'd imagined. No one asks for a diagnosis of Parkinson's. No one puts "support groups" on their bucket list of things to do. Yet as Melville said, our lives really are connected by a thousand invisible threads.

The people we meet in Parkinson's support groups are connected by some of those previously invisible threads. In support groups, these unique threads are woven together as we share our stories. The support groups help us to make connections, to remind us of the preciousness of each moment, and to appreciate more fully the deeper dimensions of giving and receiving. Some of what we learn in groups is immensely practical. Yet, when things are just as they should be, support groups also provide a portal to the mystery and wonder of life and the positive aspects that can be found in all things.

Agneta's health insurance. There is never enough. But she can be resourceful when it comes to providing her sister with a decent quality of life.

"You see this rug," Agneta said, pointing to the living-room carpet. "For two and a half years, I cooked every Sabbath dinner for a man and his family of 11." He gave her the carpet.

Lately, she has been sleeping two nights a week at an older neighbor's home for extra money, spelling the regular caretaker. "Every piece of furniture and article in this house," Agneta said, glancing around the spotless room, "has a history of sacrifice."

As she spoke, Esther, who was neatly coiffed and propped up in a recliner, with a blanket covering her delicate frame, could do little more than look at her sister. Esther's hands have stiffened into claws, and she uses a device to amplify her weak and garbled speech. Her condition also prevents her from being able to express emotion.

In the middle of describing her situation, Agneta broke down. Esther commiserated as best as she could. "I would cry, too, if I could," she said faintly. "But I can't cry."

Agneta composed herself and rushed to her sister's side. "Don't worry, I'm strong," she said, stroking Esther's hair. She explained, "I don't like my sister to see me this way." With one hand on Esther's shoulder, she added: "We are survivor types. When nine lives are gone, we have the tenth one."

Recently, Agneta got behind on her monthly \$701 rent. She came home to an eviction notice on her door. But she was able to pay it with the help of the Met Council on Jewish Poverty, which is a beneficiary of UJA-Federation of New York, one of the seven organizations supported by The New York Times Neediest Cases Fund.

She has also embarked on a project to move her sister into an apartment in her building. But first she must clear out seven layers of old linoleum and make the doorways and bathroom handicapped-accessible. "I don't have the money," Agneta said. "But I will do something."

Jackie Ebron, her caseworker at the Met Council, marveled at her determination and selflessness.

"God sends angels down among us," said Ms. Ebron, who directs the council's crisis intervention program. "If I had a sister, I'd want her just like that."

## Are you experiencing wearing off of your Parkinson's Disease medications prior to your next dose?

The Parkinson's Institute is evaluating an investigational medication that may reduce motor fluctuations and dyskinesias



Qualified research participants must be:

- Between 30 and 80 years of age;
- Must be taking carbidopa-levodopa (Sinemet®) 4 times a day (400-1000mg);
- Must be experiencing "off" periods (motor fluctuations) for at least 2 hours during the day;
- Must not be taking Sinemet CR, Stalevo, Entacapone, Comtan, Parcopa, Tasmart, Madopar or Prolopa.

If you qualify for participation, all study-related medical care, physical examinations, laboratory tests and investigational medication will be provided at no cost. Please call Liza Reys at 408-542-5626.

Log on to: [www.ppsg.org](http://www.ppsg.org)

## Blue-Green Algae Tested for Treating Amyotrophic Lateral Sclerosis

**ScienceDaily** (Dec. 22, 2010) — Nutritional supplementation with Spirulina, a nutrient-rich, blue-green algae, appeared to provide neuroprotective support for dying motor neurons in a mouse model of amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, University of South Florida neuroscientists have found. Although more research is needed, they suggest that a spirulina-supplemented diet may provide clinical benefits for ALS patients.

A spirulina dietary supplement was shown to delay the onset of motor symptoms and disease progression, reducing inflammatory markers and motor neuron death in a G93A mouse model of ALS. Spirulina, an ancient food source used by the Aztecs, may have a dual antioxidant and anti-inflammatory effect on motor neurons, the researchers said.

Their study is published in the current issue of *The Open Tissue Engineering and Regenerative Medicine Journal*.

"ALS is a degenerative motor neuron disease," said the study's lead author, Svitlana Garbuzova-Davis, PhD, DSc, assistant professor in the Department of Neurosurgery and Brain Repair at USF. "Most available treatments relieve symptoms without altering the underlying disease. However, evidence for oxidative stress has been associated with ALS and, in our past studies, we demonstrated potent decreases in markers of oxidative damage and inflammation in aged rats fed diets supplemented with spirulina or spinach. In this initial study, the diet supplement was fed only to pre-symptomatic mice. Further studies showing the diet supplement's effect on the lifespan of symptomatic ALS mice are needed to prove the treatment's effectiveness."

Specifically, when the USF researchers tested compounds found in blueberries and spirulina for effectiveness in animal models of stroke and aging in past experiments, they noted neuroprotective effects of the nutritional supplements.

The current study compared ALS mice receiving a spirulina-supplemented diet over a 10-week period with mice that did not receive the diet supplementation. The spirulina-fed ALS mice showed reduced inflammatory markers and motor neuron degeneration over that period.

"The focus of our future ALS experiments will include motor neuron counts and an examination of lifespan following dietary spirulina supplementation in symptomatic ALS mice," said study co-author Paula C. Bickford, PhD, a professor in the USF Department of Neurosurgery and Brain Repair and a senior research

biologist at the James A. Haley Veterans' Hospital in Tampa, Florida.

**PDF (Parkinson's Disease Foundation)** regularly hosts online educational seminars, or *PD ExpertBriefings* for the Parkinson's community. Their new series of six just kicked off - stay tuned for announcements about upcoming topics and dates. More than 10 recorded seminars are also available online 24 hours a day, 7 days a week

**Tuesday, March 22**

**10:00 AM – 11:00 AM PT**

**PD Expert Briefing - PD & Cognition - WEBINAR**

**Tuesday, March 22**

**1:00 PM – 2:00 PM ET**

Faculty: Alexander I. Tröster, Ph.D.

University of North Carolina at Chapel Hill

[http://www.pdf.org/en/online\\_education\\_upcoming](http://www.pdf.org/en/online_education_upcoming)

**Tuesday, April 2**

**10:00 AM – 11:00 AM PT**

**PD Expert Briefing - What's in the PD Pipeline? - WEBINAR**

Faculty: Michael Schlossmacher, M.D.

Harvard Medical School

Brigham & Women's Hospital

[http://www.pdf.org/en/online\\_education\\_upcoming](http://www.pdf.org/en/online_education_upcoming)

**Tuesday, May 24**

**10:00 AM – 11:00 AM PT**

**PD Expert Briefing - Understanding Pain in Parkinson's - WEBINAR**

Faculty: Jeffrey Wertheimer, Ph.D.

Cedars-Sinai Medical Center

[http://www.pdf.org/en/online\\_education\\_upcoming](http://www.pdf.org/en/online_education_upcoming)

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For current lists on exercise classes, and support group information/activity calendars, please log on to [www.ppsg.org](http://www.ppsg.org). These lists are maintained by **Steven Russell**.





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- ❖ Training trial takes place in your own home
- ❖ Participate for 3-months, 3 times a week for 1 hour
- ❖ Subjects will be randomly selected to play the games or be in the control group. Control group subjects will receive games after the study is complete.
- ❖ No need to own your own computer, we will provide equipment if necessary.

For more information call Study Coordinator at 415-476-5503  
or email [gamesforbalance@ucsf.edu](mailto:gamesforbalance@ucsf.edu)

**Bay Area residents with Parkinson's disease sought for clinical study using computer games**

Red Hill Studios, a Marin-based educational game developer, in collaboration with Glenna Dowling, RN, PhD and Marsha Melnick, PhD, PT and others at the University of California, San Francisco, has been awarded a grant from the National Institutes of Health to study the therapeutic benefits of specially adapted computer games using a balance platform similar to the Nintendo Wii balance platform for adults with Parkinson's disease (PD). The specialized games encourage physical movement proven effective at improving gait and balance in patients with PD where the off-the-shelf versions prove to be too fast and complicated. Drs. Dowling and Melnick are recruiting people with PD to participate in the study in their own homes. For more information on the study, call **415-476-5503**, or **email GamesForBalance@ucsf.edu**.



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