



# THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

Newsletter  Fall 2016

## **Masquerade Ball & Casino Night Fundraiser**



### **The Parkinson's and Movement Disorder Foundation**

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**Casino Night is back!** Join us on Sunday, October 23, 2016, at the Old Ranch Country Club in Seal Beach. This year we have a fun way for you to win one or **ALL** of the five great raffle prizes.

How can you win a raffle prize? Each person attending will be given \$50 to play the tables. Like in any casino, your goal is to make the most money with that initial \$50. If you are off to a slow start and want to get back in the game, you will be able to buy more chips. \$100 in chips are available for \$40. The more money you win at the tables, the more raffle tickets you will receive when you cash them in at the end of the evening. You will receive one raffle ticket for each \$10 chip you redeem. The games include Blackjack, Poker, Craps, and Roulette.

If you are not a betting person, you can cash in your chips for raffle tickets as well. Not interested in the raffle? You can donate the chips to PMDF and we will give you a donation receipt.

Now for the good stuff! **The grand raffle prize is a 3-hour cruise aboard the 42' yacht *Reverie*. You and your 9 adult guests can enjoy a relaxing cruise around Huntington Harbor. Appetizers, food, and beverages valued at \$45/person will be provided (total value \$450).** Second place prize is a 3 days/ 2 nights stay at Don Laughlin's Riverside Hotel and Casino Resort in Laughlin, Nevada (value \$125). Third place prize is an 80-minute massage at Origins Massage and Bodyworks in Fountain Valley (\$120 value). Fourth place prize is a complimentary dinner for two (\$40 value) at the Lazy Dog Restaurant & Bar located in Huntington Beach. Last but not least a \$25 gift card to Katella Deli in Los Alamitos.

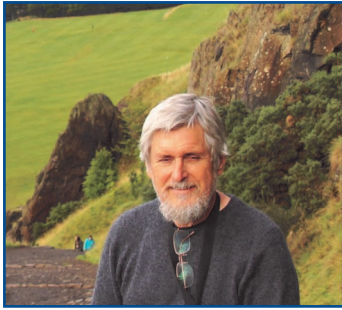
Remember this is a Masquerade Ball. We will be awarding the lady wearing the best mask and gentleman with the best mask. They will each win a \$25 gift card from Katella Deli.

As always PMDF will host a silent auction to help raise money for research. All those who are not into casino games can bid on the great auctions items we have acquired! **The featured item is a Two roundtrip coach United Airlines airfare from LAX to HCM city (Saigon, Vietnam) 5 nights, 4 star hotel in HCM, 5 nights and Hoian/ DaNang resort on November 2017 (date specific) by Four Season Travel and Tours (\$5000 value).** Please see page 6 for more details on the auction prizes!

A ticket for the event is \$150 (\$75 of which is tax-deductible). Your ticket includes dinner, wine, casino games, raffle prizes, silent auction, and the most fun you can pack into 5 1/2 hours. To purchase your ticket(s), you can go to the PMDF website at <http://www.pmdf.org/events.php>

If you are unable to attend, please consider making a donation to the PMDF to help support research into Parkinson's and movement disorders. You can make donations by mailing in a check to the PMDF or by going to the following link online: <http://www.pmdf.org/support.php>

## President's Letter



Dear friends of PMDF,

We have two big events happening very soon. We are preparing to send out our request for grant proposals. And we are holding our fall fundraiser to pay for those grants. But there are other things going on in the Parkinson's community. Here are some Orange County events you might want to check out:

### *Seminars and Webinars*

- UC Irvine Health is hosting **Parkinson's disease Symposium 2016: Current and Future Developments** on Saturday, December 3. This is a free half-day event with lectures and panel discussions. Topics include non-motor symptoms, current treatments and new developments, and lifestyle recommendations. Visit <http://tinyurl.com/parksym16> for more information and to register.
- The Michael J Fox Foundation offers "Third Thursdays Webinars" on Parkinson's research. You can register for a webinar and attend it in real time, which gives you the opportunity to ask questions. Or you can browse the list of past webinars and watch them at any time. <http://www.michaeljfox.org>; click on "Understanding Parkinson's" then "Third Thursday Webinars".
- The Parkinson's Disease Foundation offers *ExpertBriefings* on a variety of subjects. Coming on January 10 is "Pain in PD." Register at [http://www.pdf.org/parkinson\\_briefing\\_pain16](http://www.pdf.org/parkinson_briefing_pain16). Recordings of past briefings are available.

### *Support Groups*

- Parkinson's Association of Orange County has a good list of Parkinson's support groups, including groups for patients, groups for caregivers, and exercise and movement groups. See <https://paocinc.org/parkinsons-community/orange-county-support-groups>.
- A list of Parkinson's disease support, exercise, and therapy groups in more of Southern California can be found at <http://tinyurl.com/pr16supp>.

### *General information*

- The California Parkinson's support network (<http://www.calpd.info>) has links to a wealth of information about Parkinson's disease, including the topics above.

And, of course, PMDF (<http://pmdf.org/newsletters.php>) has a nice searchable collection of short articles from our newsletters about Parkinson's disease and other movement disorders.

Sincerely,

A handwritten signature in cursive script that reads "Mark Wadsworth".

Mark Wadsworth  
President

# ***Interview With Dr. Alexander Büll, 2015 PMDF Grant Winner***

by Mary Ann Chapman, PhD

As parents, it's great to know that the educational toys and activities we provide for our kids actually benefit them. Dr. Alexander Büll, one of the PMDF's 2015 grant award winners, is a case in point: he traces his interest in science to his dad who gave him science books, watched science shows on television with him, and even built him a chemistry lab in the cellar! This interest was helped along by a wonderful chemistry teacher, eventually leading Dr. Büll to pursue a PhD in physical chemistry.

Today, Dr. Büll is an Assistant Professor at the Institute of Physical Biology, University of Düsseldorf in Germany, where he studies protein aggregation. Specifically, he studies the protein alpha-synuclein, which most people believe plays a major role in Parkinson's disease. Under certain conditions, alpha-synuclein clumps together to form large aggregates in the brain. The exact relationship of these aggregates to nerve cell death and eventually the symptoms of Parkinson's disease is not yet clear, but the research of Dr. Büll and his colleagues is moving us closer to understanding.

Via e-mail, I asked Dr. Büll to tell us a little bit about his research.

## ***What are your future research plans?***

Together with collaborators from Cambridge and Lund in Sweden, we were the first, in 2014, to describe a novel type of reaction in which the aggregates found in the brains of patients with Parkinson's disease are able to multiply rapidly (*Proceedings of the National Academy of Sciences*, 2014). We believe that this reaction might be the crucial step in the spreading of the disease pathology throughout the brain. I am currently focusing on trying to understand this process in all of its molecular detail and hope that this understanding will enable us to selectively target the protein multiplication and spreading. The idea is to be able to stop further progression of the disease, possibly even before people experience any symptoms. But for

this we need better diagnostic tools, and some of my colleagues here at the institute are working on precisely this.

Another line of research that I am pursuing currently is to try and understand better why some genetic mutations in the alpha-synuclein gene increase the risk for Parkinson's. We have recently been able to push our understanding of the aggregation behavior of these mutants to a much more quantitative level than had been possible previously (Flagmeier et al., *PNAS* 2016). I am now trying to rationalize these interesting findings.

## ***What are some of the questions we need to answer in the future regarding movement disorders?***

I think a key question is whether the process of protein aggregation is a cause or a consequence of neurodegeneration. We need to know this in order to be able to decide whether targeting the process of protein aggregation is the right strategy for a therapy. If this is indeed the case, we then need to establish which step in the complicated molecular cascade leading to protein aggregation we should try to inhibit. This is where I believe my own work can make a contribution.

Another key point is that we need better ways of diagnosing neurodegenerative diseases like Parkinson's and Alzheimer's in very early stages, before the brain has sufficiently degenerated for the patient to show symptoms. This is not something I very actively work on, but I did recently publish a related paper (Costantini et al., *Phys Rev Applied*, 2016).

## ***What are some of the advances you have witnessed in movement disorder research?***



Of course my answer to this question reflects my perspective as a Physical Chemist who is studying the origins of movement disorders, such as Parkinson's disease, at the most fundamental, molecular level. A medical doctor might have a completely different perspective.

During the 10 years that I have been involved in research on the molecular origins of neurodegenerative diseases, I have witnessed tremendous progress in our understanding of the molecular mechanisms that proteins undergo and that lead to the formation of insoluble aggregates, such as the ones found in Lewy bodies in Parkinson's disease. We now have a much better idea why, and how, protein molecules assemble into large aggregates, some of which have been shown to be toxic for the cell. Of course the final proof of whether these aggregates are the cause of these types of diseases has still not been presented, but there is very compelling evidence that these aggregates do indeed play a key role in the development and spreading of these disorders. We are now able to study the aggregation of disease-related proteins at the level of the individual aggregate and the individual molecular process, and all of that even within a living cell. My colleagues and I are absolutely convinced that this level of detail is indispensable in order to be able to systematically design therapeutic and diagnostic strategies. And I believe that we are now starting to have the right level of understanding.

***Why do you think it is important for patients and/or laypeople to know about research and/or movement disorders?***

I appreciate that it must seem frustrating to patients and their friends and family that we still don't have a cure for neurodegenerative diseases in general and movement disorders in particular. In fact, it frustrates me very much, as my granddad has a movement disorder. It is important to realize that this lack of progress has essentially two reasons. First and foremost is the fact that this really is a very difficult scientific problem. For example, we don't even fully understand the role of the protein alpha-synuclein in healthy people yet, let alone in the disease. Second, the fact that research into the molecular origins of these diseases is perhaps not quite as well funded as it ought to be, given the overall impact that these diseases have. Hundreds or even thousands of scientists and medical doctors around the world are constantly

working hard to help understand these diseases better and transform this understanding into therapies. It is important for people who have an interest in this work to support it, in particular by lobbying that more funding should be allocated by the governments to this type of research. Even though it is of course not generally true that putting more money into a field of research automatically yields better solutions, more funding, together with public awareness, can make a difference, as demonstrated to some extent by the "war on cancer."

***How will the PMDF money help you to pursue your research goals?***

When I started my new position as assistant professor, I didn't have any research funding at all! Luckily, I am in an institute with a good infrastructure, such that I was able to get started anyway. Then I received the grant from the PMDF and, despite the fact that this is not a lot of money—research is very expensive—this made a huge difference. Psychologically, this award was a sign that someone had confidence in me as an independent scientist, but of course, the award also enabled me to buy specialized equipment and chemicals.

*If you would like to contact Dr. Büll to learn more about his research, you can e-mail him at [Alexander.Buell@uni-duesseldorf.de](mailto:Alexander.Buell@uni-duesseldorf.de).*



# Depression and Anxiety in Dystonia

by April Ingram and Mary Ann Chapman, PhD

The main treatments for dystonia typically focus on the symptoms of muscle overactivity. Depending on the type of dystonia, treatment may include drugs that are taken orally, botulinum toxin therapy, or deep brain stimulation.

However, as more dystonia research is conducted, there is a growing awareness of the importance of non-motor symptoms. Non-motor symptoms may include mood alterations, as well as problems with attention, memory, pain and sleep. In fact, a recent study found that nearly a third of people with cervical dystonia experience depression, in contrast to only 14% of individuals without cervical dystonia.<sup>1</sup> Similarly, 42% of those with cervical dystonia experience anxiety disorders as opposed to only 8% of those without the condition. Other studies have reported comparably high rates of depression and anxiety in those with other types of dystonias.<sup>2</sup>

Depression and anxiety are not uncommon in people with chronic health conditions. Indeed, these symptoms are probably natural reactions to being diagnosed with a long-term health disorder. This can make it difficult to determine whether depression and anxiety are reactions to the disorder or are caused by the underlying disease process itself. Although more research is needed, some evidence suggests that depression and anxiety in dystonia may be related to the same underlying brain disturbance that causes motor symptoms.<sup>2</sup>

Regardless of their cause, depression and anxiety have a substantial negative impact on people with dystonias.<sup>2</sup> Patients should be alert to these symptoms and should not hesitate to talk with their healthcare providers about the range of treatment options available.



## Ref-

### References

- Smit M, Kuiper A, Han V, et al. Psychiatric co-morbidity is highly prevalent in idiopathic cervical dystonia and significantly influences health-related quality of life: Results of a controlled study. *Parkinsonism Relat Disord.* 2016 Sep;30:7-12.
- Kuyper DJ, Parra V, Aerts S, Okun MS, Kluger BM. Nonmotor manifestations of dystonia: a systematic review. *Mov Disord.* 2011 Jun;26(7):1206-17. 3.

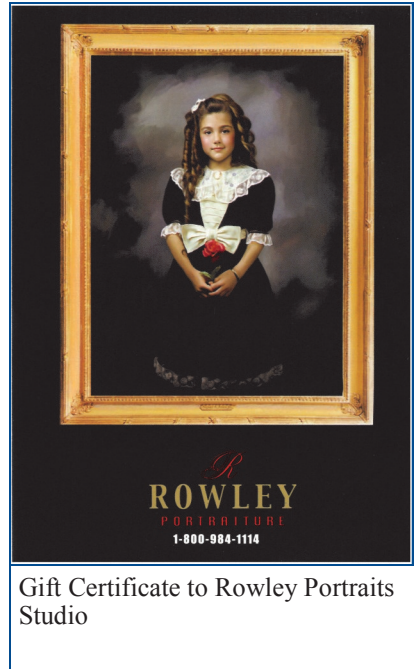






# Origins

MASSAGE AND BODYWORKS  
1 hour massage (\$90 value)





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[www.pmdf.org](http://www.pmdf.org)

## **OUR MISSION**

To support basic and clinical research into the causes, treatments and cures for Parkinson's disease and other movement disorders such as dystonia, myoclonus, spasticity, and tremor.

The Parkinson's and Movement Disorder Foundation is committed to working with other organizations that have similar philosophies in an effort to bring together expertise from both basic and clinical science perspectives.

We are dedicated to enhancing the quality of life for those who suffer from movement disorders and their families, through research, education, and community outreach.