by Becky Strong

Last Spring I attended the annual IPPF meeting in Philly. I had a wonderful time and learned so much as a newly diagnosed patient and a nurse. One of the speakers, Dr. David Sirois said something that really struck home with me. We, as patients, need to be the one to educate doctors and others about our disease. We have the power to get the word out there. WOW! He was so right about that.

I took that message home with me, and on my next appointment in the oral surgery clinic at the University of Michigan, I told my doctor, Dr. Carol Ann Murdoch-Kinch, about my time at the conference, what I learned, and offered to speak to any of her students, if she wished. She was really surprised I would offer, and told me that she would take me up on it. On February 10, 2011 I got my chance.

Pemphigus was scheduled to be the topic of Grand Rounds at the University of Michigan School of Dentistry. Dr. Murdoch-Kinch asked me to speak about my experience leading up to diagnosis and then treatment with pemphigus. She also wanted me to talk about my feelings about the length of time it takes to be diagnosed and how pemphigus affected my life. I believe she and her 212 students got more than they bargained for on that Thursday morning. You could hear a pin drop during my lecture.

Continued on page 4...
As you can see from the “numbers” (pages 8-9) 2010 was an extraordinary year in advancing care for P/P patients. More people calling on us for information and support, more Peer Health Coach’s answering more questions from more countries, more vised the website and stayed there to learn, and most recently, an new community of self-support has blossomed on the IPPF Facebook® page.

Still, we see other numbers that give us pause. Few of the newly diagnosed participate in the original Email Discussion Group — where some of the seen-it-all, fonts-of-wisdom built the first P/P “community” — and few of those old friends from the EDG have made the transition to Facebook® where nearly 400 people from around the world share hope and advice. We contemplate whether our community has grown so large as to feel fragmented or whether we are supporting ways to serve each type of need, although they come far and wide.

Of even more concern is the reality that after people achieve illness improvement or remission they participate less and less with sharing, advising, or educating others. It can have the effect of draining the community of the wisdom of those who persisted and succeeded, and the hope that is evidenced by another’s health improvement. This same phenomena is reflected in the individual financial support for the IPPF. While most people do make a donation to the Foundation early in their illness, as time passes this drops off significantly: in a given year only 1/10 people who request and receive service from the IPPF make a donation. The IPPF is committed to helping every patient at no cost, but at the same time depends on your generosity to continue and expand valuable services for everyone. Please consider making a donation today!

We recognize that the battle is not over when we help one person at a time, the battle is just getting started. It’s not just about one person getting better — it is also about hundreds of thousands with symptoms getting a fast and accurate diagnoses, about tens of thousands of doctors having knowledge to treat effectively and thousands of patients who need access in their community to a doctor who can help. It’s about the many hundreds of thousands who will come after you, who’s lives will be changed by what we do now … what we invest now.

Your Board of Directors after much internal committee work and analysis has approved the following projects to support three key initiatives: the first, a result of Board feedback session at the last Annual Meeting (Philadelphia, 2010) is a robust Doctor Awareness Campaign to assess doctor familiarity of signs/symptoms/treatment and target strategies to achieve faster diagnosis and more effective treatment; the second, the Best Practices Consensus Conference (2012), where, on the heals of our very successful scientific meeting in November, 2010, we are planning a pivotal meeting of leading experts to develop clear "best practice" principles that help us influence insurance benefits and doctor treatment awareness; and finally, ongoing with the Registry, to celebrate 500 volunteers enrolled and to learn from the aggregated data available for the first time ever, what seems to be working and what not. This will, and is, truly driving science discovery and patient priorities.

I look forward to seeing you all at the Annual Meeting in Detroit, May 20-22, 2011.

Molly Stuart, JD
Chief Executive Officer
molly@pemphigus.org
Thank You to our Supporters!

The following people made donations in November/December 2010 and January 2011. You can donate at any time by visiting www.pemphigus.org.donate.

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Thank you for your support!
I told them that my issues began in September 2008 and then led them through an emotional and terrifying journey filled with all the gory details of pemphigus that led to my diagnosis in February 2010. The students had the opportunity to learn about this disease from first hand experience, not a textbook. I taught not only through the words from my mouth, but the anger that would come and go in my voice, the tears in my eyes, and the feeling of eventual relief that I felt.

After telling my story for one hour, students AND faculty asked me questions. Some questions were very personal, others very clinical. They wanted to know about treatments, the emotional and mental impact on me and my family and they asked how the doctors who treated me and missed my diagnosis would act toward me after diagnosis. I have got to tell you, my favorite comment came from a second year student. He said, “Your experience was horrible. How come we don’t hear more about this disease? It seems like we need to get the word out there.”

At last, the “A-HA” moment!!! One patient asked one doctor to speak to her class. One student asked one question that proved the whole room got it. The power of ONE.

I went into this whole experience wanting to get pemphigus into the minds of the people who could help the most, to get them to recognize and consider this disease in patients who have mouth lesions that are not healing. I didn’t care if they remembered my name or my face. Just remember the disease! I wanted to bring this disease off the page of a textbook and send a real life message. I left knowing those students won’t forget pemphigus or me.

After the lecture period, students and faculty came up to me and told me how much courage I had to speak about pemphigus and the impact it had on me. Students were talking to me with tears in their eyes, and most to I spoke with would give me a hug. It turned out the Dean was there and she and my doctor think it would be a good idea if I spoke at the School of Medicine. It turns out that a member of the faculty also teaches at another university in our area and wondered if I would be willing to speak there as well. I would do anything to help get our message out and bring awareness to our disease.

When I went home that day, I thought just how much just one person can make such a huge difference. One person got it in her mind to start IPPF. One person in a group had the thought to have an annual meeting. One person spoke and a whole room listened. One person took a message home and spoke with 212 graduate students. I guarantee one person went home and told somebody else about what they heard.

That is truly, the power of one.

We, as patients, need to be the one to educate doctors and others about our disease.
Your IPPF Medical Advisory Board met at the American Academy of Dermatology Annual Meeting in February to outline their goals for the next two years. We marked the sad passing of former MAB Chairman, Jean-Claude Bystryn, and welcomed the volunteers who took up the reins, Dr. Vicky Werth as the Chair, and Dr. Sergei Grando as the Vice-Chair. The MAB, keeping in mind the mission of the IPPF, continues its focus on the three key goals of the IPPF – Patient Support, Doctor Awareness and Scientific Discovery and promises to move forward in these areas.

**Patient Support**

Recognizing that one of the key “values added” that the MAB provides members of the IPPF is access to their very specific expertise -- especially when there are so few that have such knowledge. To help grow this access of IPPF patients to the wisdom of these experts, the MAB has agreed to contribute to a Town-Hall style teleconference every few months. These meetings will include sharing information on specific topic(s) or facilitating Question & Answer sessions.

**Building Doctor Awareness**

The MAB’s seminal task in improving the care that patients get in doctor offices will focus on developing a consensus statement on the most effective treatment protocols. This will aid in creating best practice guidelines for doctors not familiar with treating P/P -- like what side effects to look for or how to evaluate the tapering of prednisone.

The MAB will elect a Steering Committee to articulate the specific outcomes, and assign teams and action items. These will include conducting worldwide research to collect consensus statements already concluded. In some countries, for example, governments require doctors to follow a standard, more narrowly defined, or even a radically different set of procedures and milestones than in the US (and these protocols have already been decided and published).

In addition, the IPPF will collect models of success for the process of developing a set of guidelines for non-experts to follow. Concurrently, the MAB and the IPPF BOD will pursue opportunities to fund this project to bring together these leading clinician-scientists for a two day meeting. The goal of this meeting will be the authoring an authoritative paper on present/future/best treatment practices. Then we will really have the opportunity to shape the future of better health.

**Scientific Discovery**

Finally, in order to ensure that there will be enough (a usefully large and representative sample) data by the 2012 Consensus Meeting to eval-

Continued on page 7...
Support Needs, Sources & Giving Back

Life for healthy people usually does not feel like a lot of unknowns on a daily basis, even if daily routines changes frequently. Everyone knows that they could step into the street and be hit by a bus, but few actually lose sleep over that possibility.

If diagnosed with something well known and understood, such as heart disease or cancer, there is usually an immediate medical protocol for the patient/person to participate in – and diagnosis/detection is usually reliable. Once the protocol and specialists are in place (sometimes after only one telephone call) the patient has to deal with the diagnosis and perhaps lifetime consequences. There will be a lot of professionals available, often including insurance nursing coaches, and friends, relatives and the general public will probably at least understand the basics of the situation. There will be literature and information readily available, and support will probably be offered. And, there are often investments in cures or at least “races for cures” for these “popular” illnesses.

However, with rare “orphan” diseases the patients and treating doctors often find themselves facing an uphill battle to properly diagnose, find best treatments, implement them and get insurance coverage. Even after the struggle to get a proper diagnosis, the path is still challenging. Now you know what you have - this strangely named, rare, disease that people have never heard of and which even many doctors have never seen before. Standardized treatments don’t exist or don’t work for enough cases, too few meds are approved specifically for treatments causing insurance challenges, and even the scientists don’t really have answers. Now, the world becomes a very different and scarier place, filled with even more uncertainty.

Fortunately for P/P patients, there is help in the form of the IPPF, medical specialists and expert patient health coach advisors, plus community access through Facebook®, Forums or Email Discussions can connect you with others just like you and with more information. The IPPF website has won awards for its great resources (although there is a lot to process especially in the beginning). Since your treating physician may not be an expert, information and support is available for doctors too!

Behind the scenes the Medical Advisory Board, Board of Directors and IPPF employees are also working tirelessly to continue to keep the Foundation running smoothly and to locate necessary resources, including funding for projects. The Annual Doctor/Patient Meeting provides an arena for dissemination of education, information and support for patients and family/friends.

Local support groups continue to meet, and some have been around for more than a decade. The local support leaders often give tirelessly of themselves, even once they may have reached their own remissions. Those who continue to give, stay involved and are dedicated to helping others are a very special and sometimes under-appreciated group. Many patients only stay involved when they are new to the illness and trying to make necessary adjustments to this new life.

Others do what they can by giving generously financially in order for the Foundation to continue to provide its free services. No one is sent a bill. Instead, everyone is asked to give as much as they can, in any way we can, at least annually. Patients can ask friends and others to donate to the organization directly, in someone’s name or in honor of an event or can support this work through buying from IPPF partners, including purchasing beautiful holiday and greeting cards which can be ordered through www.pemphigus.org/cards. It’s a win-win situation.

Continued on page 10...

Dr. Terry Wolinsky-McDonald is a licensed clinical psychologist in the Pittsburgh, Pa. area. She is a member of the IPPF Board of Directors and frequent contributor to the Quarterly. Her articles focus on the psychological aspects of living with P/P in patients, caregivers, and family members.
The IPPF has completed the process of translating the Registry into a Spanish version and receiving Review Board approval for protection of research data and subjects. Instrumental in the process was our IPPF Intern from Cristo Rey High School.

Kevin Cruz, a bilingual student, started at the IPPF last June and painstakingly matched each English-to-Spanish question (and the many possible answers) that comprise the registry survey. It was a task we could not have done without his expertise.

Following Kevin’s completion of the conversion to Spanish, two doctors that we met at the IPPF’s JC Bystryn Pemphigus & Pemphigoid International Science Meeting in Bethesda, MD in November 2010 (read more about the meeting in the Fall 2010 Quarterly, Issue #63) agreed to read, edit, and confirm for medical accuracy. A huge thanks go our to Dr. Agustin Espana (Spain) and Dr. Lissie DeKok (Venezuela) for their translation supervision and for their dedication to getting a more full picture of these diseases by including data from other critical regions.

We have had offers and requests for translation into Russian and German and we hope to have resources to include these as well. The registry now has almost 500 participants and will begin to be useful for science inquiry when we get to about 1,000 sets of data.

You can access the Spanish version of the Registry online at, www.pemphigus.org/registry and select the Español link. Paper copies are available by calling (916) 922-1298 option 3 or emailing registry@pemphigus.org.

...continued from ACTION!, page 5

P/P Registry Update: ¡Ahora en Español! (now in Spanish)

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...continued from ACTION!, page 5
by the numbers

1,165,796 individual pages viewed on the IPPF websites
92,114 unique visitors to the IPPF websites
6,658 activities conducted by the IPPF such as email, phone calls, and packages sent
521 patients made specific requests for help from the IPPF staff
1,493 contacts added in 2010
90+ countries we have patient contacts in

19,106 post views 879 feedback from users
343 likes in 2010 275 active users
72% of visitors are FEMALE
44% of users are over 45 40% come from Google

www.pemphigus.org/facebook
1 in 10 people who request and receive service from the IPPF make a donation

The IPPF needs EVERYONE’S support as we work towards

ROBUST AWARENESS CAMPAIGN
to assess doctor’s familiarity with P/P signs, symptoms, and treatment strategies

BEST PRACTICES CONSENSUS CONFERENCE
where leading experts will develop “best practice” principles to influence insurance benefits & doctor awareness

P/P PATIENT REGISTRY
as patient information helps drive discovery and priorities
Navigating your new and more challenging life with P/P will be a lifelong process. Patients and their caregivers feel like they are jumping through hoops, and sometimes jumping through flaming hoops. The IPPF and its resources are always available for no charge. As patients are feeling better, this is a good time to try to give back. Helping others is a gift that keeps on giving. Remember to gauge your own support system and ways others can/cannot help. Also, remember that caregivers often need their own support systems and validation. As previously said, support and possibilities for support are all around; learn, make a phone call, get on the computer, start or participate in a local support group.

Hopefully, patients’ physicians are open-minded, well informed (or willing to make phone calls, request help or advice, and make referrals if necessary). If the physician is an advocate for the patient, they are part of the support system. If not, it will be difficult to get certain treatments or protocols, especially since not all patients respond the same way to all approaches and some patients cannot even attempt some treatments because of other preexisting conditions or allergies. The best treating doctors will make sure to schedule appointments at various intervals, in addition to emergency appointments. They will also coordinate care as necessary with other treating physicians and medical professionals.

Remember, support is there in so many forms. Utilize it. Be it. Share what you can. Imagine what we could accomplish if everyone gave time, energy or money to support an accurate and fast diagnosis, good treatment options and excellent personal support available for all?

I am looking forward to seeing old faces and meeting new people at the Annual Meeting in Detroit this May.

INTERNATIONAL SUPPORT

CANADIAN PEMPHIGUS AND PEMPHIGOID FOUNDATION (CPPF)  
http://www.pemphigus.ca

AUSTRALASIAN BLISTERING DISEASE FOUNDATION (ABDF)  

ASSOCIATION PEMPHIGUS - PEMPHIGOÏDE FRANCE (APPF)  
http://www.pemphigus.asso.fr/

ASSOCIAZIONE NAZIONALE PEMFIGO/PEMFIGOIDE ITALY (ANPP)  
http://www.pemfigo.it

NETWERK NEDERLAND VOOR PEMPHIGUS EN PEMFIGOÏD (NNPP)  
http://www.pemphigus.nl/

PEM FRIENDS (UK)  
http://www.pemfriends.co.uk

SPANISH FACEBOOK GROUP  
http://tinyurl.com/ippf-facebook-es

If you have a group you let us know so we can help spread the word!
With a specialty degree in Dermatology and a sub-specialty called Dermatologic Immunology/Clinical and Laboratory Immunology, Dr. Grant J. Anhalt is also a golfer (like that’s a surprise)! His lowest handicap has been a 13, but currently an 18…. “and climbing” he states. The cherries are disappearing in that pie, eh doc?

Dr. Anhalt was born in Shaun-avon, Saskatchewan, Canada (that is quite a mouthful) - which is a tiny town just north of the Montana border. “Do not go there in the winter,” he says.

He finished medical school and residency in Winnipeg. Then he was accepted to the dermatology training program at the University of Michigan. For an unknown “Canuck” (his word, not mine) this was a marvelous opportunity! Although he had interviewed with most of the Ivy League schools as well as the NIH, he decided to stay at UofM and work with Dr. Luis Diaz because he had the most appealing ideas and projects involving the high-impact, blistering diseases, pemphigus and pemphigoid; and Michigan is one of the best training programs in the United States.

He did his research fellowship with Dr. Diaz. During this fellowship, Dr. Diaz and Dr. Anhalt managed to produce the first animal model for pemphigus, using a neonatal mouse. That model has became the standard for examining how the disease behaves. Because of this success, he knew this would be his path in life for the next 30 years. The entire team, consisting of four doctors, one secretary and one technician were recruited to join the faculty at Johns Hopkins in 1982.

Down the road a little bit, he saw a patient that had a very puzzling illness. At different time points, he was thought to have drug eruptions like pemphigoid or Stevens-Johnson syndrome. He also had an underlying lymphoma. Dr. Anhalt was not sure what he had, but he did have evidence of pemphigus antibodies, which clinically did not make sense. He purified the patient’s antibodies and injected them into a neonatal mouse and that caused the typical lesions of pemphigus. With the help of Dr. John Stanley, the patient’s antibodies recognized a unique group of epidermal antigens, and Dr. Anhalt was then able to find a number of patients who had a similar disease and identical antibodies. Because all of these patients had an associated lymphoid malignancy, he named it paraneoplastic pemphigus.

He views the development of the animal model for pemphigus, and the first description of PNP as the major accomplishments in his career. Managing to publish articles on both subjects in the highly esteemed New England Journal of Medicine was no small deed considering they dealt with dermatology issues; usually more common diseases such as neurological, pulmonary and rheumatologic get more pages in leading journals.

I asked him if there were distinctive patient stories he remembers in his career. One in particular was about 20 years ago when a young man who had horrible pemphigus and was close to death contacted him. He had been treated in New York and at Yale, but...
his disease was out of control. Rituximab was non-existent, so using the treatment combination of cytoxan and plasmapheresis, Dr. Anhalt turned his disease around and he recovered. One of the nasty side effects of cytoxan is that it can cause infertility. Thinking ahead, they managed to bank the patient’s sperm before treatment, and the patient now has two beautiful teenaged children! He continues to be in a drug-free, complete remission. The grandparents still send Dr. Anhalt bottles of wine every Christmas as a thank you!

Another memorable moment was when asked by a rheumatologist at Hopkins to see a woman from New York. She was totally crippled by bone pain, fatigue, and pig-headed “hives”. She had seen about 50 “experts” in New York and Los Angeles without any relief. Her broad workup showed that all she had was an underlying asymptomatic monoclonal gammopathy (this means an elevated level of a specific protein in the blood). Recognizing that she had an extremely rare disorder called Schnitzler’s Syndrome, he put her on and injectable biological drug that is used for rheumatoid arthritis. Within 24 hours, she was symptom-free for the first time in eight years.

Dr. Anhalt says key advancements in P/P from a physician perspective, include several remarkable landmarks, including the identification of the pemphigus antibody by Drs. Beutner and Jordon in the 60s, the identification of the pemphigus antigen by Dr. Stanley, and the development of the animal model for pemphigus by Drs. Diaz and Anhalt in the 1980s. From a patient standpoint, the only thing that matters is getting rid of this terrible disease.

In the early 90’s, Janet Segall, founder of the IPPF, contacted Dr. Anhalt to help with this endeavor. “So many patients have told me that during their ‘darkest days’ the single most important thing that brought them through their struggle was the knowledge that there were other people out there that were also dealing with this. There was hope, and there was a mechanism by which they could be connected with physicians who actually knew something about the disease and how to get them beyond this.” An important role of the IPPF remains in patient and physician education. Dr Anhalt was forward thinking, even in 1994. He knew that “only through the internet we would be able to communicate and educate about these orphan diseases. Every disease now, no matter how common or rare, has its own constituency and demands for money and attention. We can only succeed if we are more effective in this competition, and that competition is taking place online.”

Reminding us of the challenges facing research funding -- especially for rare disorders -- Dr. Anhalt says, “Patient supported Foundations do not have the money to support basic research, which is incredibly expensive (many hundreds of millions), and is funded by research organizations such as the NIH and pharmaceutical companies, however, the recent initiative by the IPPF to form a Patient Registry and biological specimen collection is incredibly
important to future research, and is something that they can actually complete -- given some additional money through strong fundraising efforts.”

Doc has a very busy schedule! With the love of teaching in his heart, two mornings a week, he reads immunofluorescence biopsies in the department with the faculty, residents and fellows to help them understand the immunologic diagnosis of these diseases. Personally, I enjoy a good mystery. Two afternoons, he works one-on-one with the residents seeing patients at Hopkins. Wednesday mornings are slotted for rounds. Residents are taught how to diagnose and manage these very difficult clinical cases.

...the single most important thing that brought them through their struggle was the knowledge that there were other people out there that were also dealing with this.

On a personal note, Dr. Anhalt has been my lifesaver for the last 10 years! He can be very technical like any other physician. But he has drawn me pictures because my brain does not always follow the medical jargon. Sometimes we agree to disagree, and we are both okay with that. He is more than my doctor, he is my friend and I love him with all my heart. He loves me too, although he does not say it all the time, I coax it out of him along with a chuckle. Like he has a choice…please!!

Dr. Anhalt is married with two grown sons and an adorable little dog. He spends what spare time he has with his family and getting haircuts. He is asked to give talks all over the world and takes his wife Audrey with him when possible. Together, they enjoy visiting and sightseeing when time allows. His hobbies, besides golfing, are coin collecting and woodworking. He lives in Maryland and I believe somewhere on his feet there are roller skates, although I have never seen them!
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MAY 20-22, 2011

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☐ Home  ☐ Work

City  State/Province  Zip/Postal Code  Country (other than US)

Daytime Phone:  ☐ Home  ☐ Work  ☐ Cell (______)

Email:  ☐ Home  ☐ Work

### DISEASE INFORMATION

- □ PV
- □ PF
- □ PNP
- □ BP
- □ CP
- □ OCP/MMP
- □ Other __________________
- □ None

### HOW TO REGISTER

- Register Online: [www.pemphigus.org/2011](http://www.pemphigus.org/2011)
- Call our offices: (916) 922-1298 x1003
- Contact your Peer Health Coach
- Mail this completed form with payment to:
  IPPF AM Registration, 2701 Cottage Way #16, Sacramento CA 95825

Registration cannot be processed without payment. Payment must be in US funds. All cancellations must be received in writing. For cancellations postmarked on or prior to April 29, 2011, we will refund registration costs less $25 administrative fee. Cancellations postmarked between April 29 and May 13, 2011 may be refunded up to 50% of the registration fees. We may be unable to make refunds after May 13, 2011 due to food, beverage and material costs. We will gladly transfer your fees to another person as a scholarship or credit you with a tax-free donation.

### Annual Meeting Registration Fees Postmarked by:

<table>
<thead>
<tr>
<th>Registration Fee</th>
<th>Cost</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular and Onsite</td>
<td>includes attendance for all three days, materials, food/beverage during scheduled meeting times, two complimentary drinks at Friday’s Welcome Reception and Saturday’s Mixer. Subject to change without notice.</td>
<td>$225</td>
</tr>
<tr>
<td>Daily - if you only plan on attending one day; DO NOT select if you paid for a full-price registration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Friday Night Reception</td>
<td>$50</td>
<td></td>
</tr>
<tr>
<td>☐ Saturday</td>
<td>$125</td>
<td></td>
</tr>
<tr>
<td>☐ Sunday</td>
<td>$75</td>
<td></td>
</tr>
<tr>
<td>Caregiver Badge (may only be purchased with a paid registration)</td>
<td>$50</td>
<td></td>
</tr>
</tbody>
</table>

Name to appear on caregiver badge:

- Event Platinum Sponsor (1 table, 4 passes, logo included online/printed materials) * | $10,000 |
- Event Gold Sponsor (1 table, 2 passes, logo included online/printed materials) * | $7,500 |
- Event Silver Sponsor (1 table, 1 pass, name included online/printed materials) * | $5,000 |
- Event Sponsor (1 pass, name included online/printed materials) * | $2,500 |

### Scholarship Donation

Please help someone else attend this year’s meeting.

### Tax-Free Donation

Your donation goes to support current and future programs and research.

**Total Enclosed**

* A member of the IPPF will contact all Event Sponsors to coordinate additional details.

- ☐ Check/Money Order made payable in U.S. funds to IPPF  ☐ VISA  ☐ MasterCard

VISA/MC # __________ - __________ - __________ - __________  Exp. Date: ______ / ____  Security Code: ______

Billing Address (if different from above): ______________________________________________________

Signature: ___________________________________________  Indicates you agree to have your card charged.