



**Your Patients' Voices Matter!  
How to Engage Patients in  
Preserving their Access to  
Compounded Medications  
and the Resources to Help**

**PROTECT ★ PROMOTE ★ ADVANCE**

**[IACPRX.ORG/CCH](http://IACPRX.ORG/CCH)**



# Disclosures

Patricia Storey and Kim Hansen declare no conflicts of interest, real or apparent, and no financial interests in any company, product, or service mentioned in this program, including grants, employment, gifts, stock holdings, and honoraria.



# Objectives

- Describe the value of P3 and the original P2C2 in successful advocacy efforts to protect access to customized medications.
- Explain why drug shortages and patient access to medications are safety issues.
- Discuss how pharmacists can obtain testimonials through their own websites.
- Explain how to get patients involved in advocacy and the best way for patients to contact the Congressmen that pharmacists met with at CCH.



# DQSA: Lack of Access is a Safety Issue

- The drug shortage issue is a national crisis.
- Patients are going without vital, life-saving medications.
- Compounding is a real solution to this crisis and can provide immediate help to patients whose life and well-being depend upon access to these medications.



# Drug Shortages Increasing

- Shortages have been on the rise for years, recent natural disasters have exacerbated the problem.
- Compounding pharmacists provide solutions by working with providers and patients, hospitals and surgery center to make medicines available.
- Collaboration between state-licensed and regulated compounding pharmacists and providers in hospitals and other healthcare facilities is a long-standing solution to shortages.



# Examples of Unavailable Meds with NO Suitable Substitute

## Safety Issue When Patients Can't Get their Meds

- Thyroid shortages

## Life-Sustaining

- Sodium Bicarbonate

HOW DO WE PROTECT ACCESS?? - [ADVOCACY](#)



# History of Advocacy - P2C2 to P3

- IACP was formed in 1991 by some PCCA members and its original name was Patients and Professionals for Customized Care (P2C2). In 1996, the Board of Directors legally change its Articles of Incorporation to reflect the name change to **International Academy of Compounding Pharmacists (IACP)**.
- About 2003, the name P2C2 was revived as the patient/physician advocacy group.
- P2C2 became **Partnership for Personalized Prescriptions (P3) in 2014**.



## P3: EDUCATE – ADVOCATE - PROTECT

- Learn more about how **personalized medications** are making a difference.
- Give patients the latest information on how they can **protect their access** to compounded medications.
- **Spread the message** about the value of customized medications.  
Tools on <https://www.p3rx.org/share.php>
- Join the Partnership for **Personalized Prescriptions** to take effective actions.



# P3Rx.org

**BREAKING NEWS** Waltham Pharmacy Takes the Non-traditional Approach to Medicine [More Information](#)



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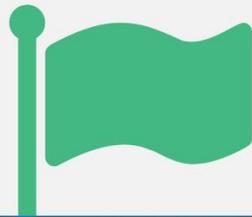
[LOCATE A COMPOUNDER](#)

[CONTACT US](#)

Join P3 to get the Latest News



## Contact Congress!



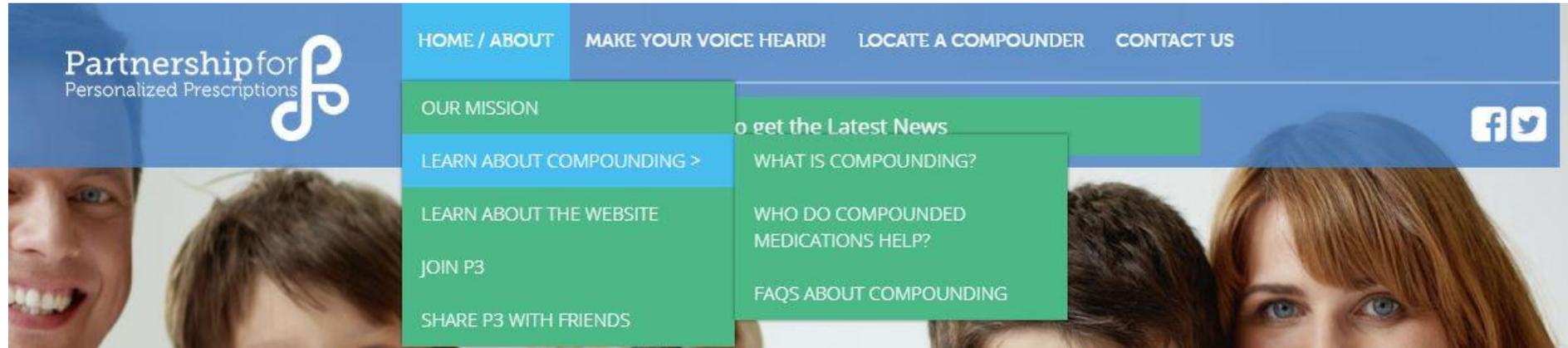
### Take Action

Help keep compounding a vital treatment option. Let your communities, the media, and your Congressional representatives know how you rely upon compounded medicines. Tell them that you are committed to making sure they remain available to patients who need them!

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# Features of P3 Website



[IACPRX.ORG/CCH](http://IACPRX.ORG/CCH)



# The Power of Testimonials

- People trust other people. (Trip Advisor)
- Ask for your patients and practitioners to help protect access to compounded (or to help grow your business) so that you can help others.
- Provide a couple examples. Short is good.
- Video is impactful – get a signed release. (HIPAA)
- Google. Yelp. Add a form with release to your website with a release.
- Share Your Story <https://www.p3rx.org/share.php> (IACP not a health care provider)



# Spread the Word

- Information in the pharmacy
- Newsletters - print or email
- Blast emails
- Postcards – hand out or mail
- Bag stuffers



# The Power of Emotional Connections

**PRINT IS MEMORABLE.**

*Print creates an emotional connection.*

*Print builds relationships.*

**Physical material is more “real” to the brain, involves more emotional processing, is better connected to memory, with greater internalization of ads- all important for brand associations.**

(FORBES)

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# Social Media

- Facebook – most used
- Instagram - post your photos with hashtags
- Twitter – for hot news
- Google My Business – free ad space – good for 7 days



# Contact Congress!

Make it easy!

Tell your patients the best way to contact the Congressmen that you have met with at CCH.

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# Kim's Introduction to Compounding

- Started working in a small independent pharmacy while attending high school
- Began as a clerk and gradually became a technician.
- Documented prescriptions on profile cards in the days before computers, USP795, USP797, USP800, HIPAA and third party adjudication



# Kim's Introduction to Compounding

- Was introduced to compounding creams, liquids and capsules
- Knew I had found my calling and could see very early on the value of customized medications
- If I could see the tremendous value all those years ago, certainly I can help others see it as well.
- New innovative dosage forms have expanded our ability to help more patients improve their quality of life.



# Identify Your Best Advocates

- Get to know your patients
- We are the most accessible member of the healthcare team and nobody knows our patients better than we do!
- You all know patients that are already fierce advocates and freely share their journey.
  - mothers of children with autism
  - menopausal women who want to maintain their quality of life



# Identify Your Best Advocates

- Dedicated pet owners
- Cancer patients
- Grateful family members of hospice patients
- Your top prescribers see the benefits of custom therapies for their patients and do not want to lose this powerful tool
- Call those passionate patients and caregivers! They love to share their experiences so others can benefit



# Its Personal-What Works For Me

*Compounding pharmaceuticals have helped our son and are a necessary part of his treatment. One prescription he takes is a custom nasal spray that has to be compounded once per month. It can't be purchased anywhere. It does not contain any additives or preservatives, is specific to his disability, and is necessary for our son's optimum behavior and functioning. Our son has many allergies and intolerances. He can't tolerate gluten, casein, starch, dyes, glutamates, gelatin, corn starch, high fructose corn syrup or anything processed. Many drugs contain these offending ingredients. If our son is exposed to these he does not sleep, becomes hyperactive, and aggressive. It has been through trial and error and testing we have discovered this. Without knowing this our son would have inadvertently been placed on heavy duty anti-psychotic drugs instead of properly removing the offending ingredients that he can't tolerate. Compounding Pharmacists can formulate custom prescriptions without offending agents. Without compounding pharmacies our son would not be able to access any prescriptions. He would suffer and everyone around him. A child experiencing a negative reaction from a drug can be handled but an adult would land themselves in jail. Ibuprofen, a common pain reliever, is compounded for our son. He must take it while undergoing IV treatment. It helps reduce headache pain due to the IV medication, but if it's not compounded he will not be able to take anything and suffer unnecessary pain and inflammation. Our son also has cerebral folate autoantibodies. Consuming any dairy or casein found in many prescriptions will block folate from binding to receptors in his brain despite supplementing with folate. The Pharmaceutical industry needs to start thinking about patients first rather than profits. Stop trying to eliminate compounding pharmacies. There will always be patients who can't tolerate pharmaceuticals and will need custom compounding.*

**- T. Ryan, C. Ryan & Theresa Farrell Ryan DMD**



# Its Personal-What Works For Me

Request testimonials via your social media feeds-both your pharmacy and personal accounts:

*When my Lyme Disease was really bad the joint pain was unbearable and nothing helped. A compounding pharmacy made my topical pain reliving cream- it was amazing. Best pain med ever, and it wasn't another pill. Now I'm a peri-menopausal woman with no testosterone. I get testosterone compounded in a cream and it is life changing for me. I have energy again. Big pharmaceutical companies can't replace that.*

**L. Odell-Wyche**



# Its Personal-What Works For Me

- Engage your most active prescribers! They are very interested in patient outcomes and really don't hear about our regulatory challenges unless we share that with them.
- Ask your prescribers to share their testimonial and encourage patients to do the same.



## Its Personal-What Works For Me

*As a physician, there are times that I can't offer a commercially available product to my patient to help with their condition and compounding has offered them solutions not otherwise available. I have patients with food allergies and sensitivities and being able to have medications made specifically for them that avoids their allergens is lifesaving and offers piece of mind. I have also personally benefited from compounding and feel that this is a very valuable option that I would like available for my own healthcare as well as my patients.*

**- T. Odell**



# Its Personal-What Works For Me

*My name is Peta Cohen. I am a clinical nutritionist working in my private practice since 1996. The focus of my practice in pediatrics, particularly the treatment of children with autism, ADD/ADHD, Sensory Integration Disorder, Genetic Disorders, and inborn errors of metabolism, as well the complex adult patient, has demanded the need to provide a delivery system for pharmaceuticals and nutraceuticals that goes beyond what is available through both the pharmaceutical and nutrition supplement industry. Creating an opportunity to restore the body back to balance is not an option, but a fundamental demand of the provider patient relationship and cannot be achieved through dietary modification alone. If a nutrient or drug is required to leverage healing and a restoration of health there needs to be an appropriate delivery system to ensure the intake and uptake of this support. Without the option of compounded medications and supplements I would never have had the opportunity to impact the life of so many individuals.*

**- Peta Cohen, MS., RD Clinical Nutritionist/Metabolic Specialist, New Jersey**



# Its Personal-What Works For Me

- Gather patient emails and enter into PK or other pharmacy software
- This is a valuable database that can be used to send emails requesting testimonials via Mailchimp or Constant Contact
- Use the email system to encourage patients and practitioners to join the P3 advocacy site
- Talk to your patients! Most of them do not know the regulatory challenges we face or how much that threatens our ability to continue to provide their individual therapies.



# Its Personal-What Works For Me

- Educate patients so they can advocate for themselves
- Share that you attend CCH and visit with your representatives and encourage them to do the same.
- We print bag stuffers directing them to the P3 advocacy site
- Postcards can be printed professionally and inexpensively using Vistaprint



# What Works For You?

- What other ways have you been successful in engaging your patients and providers?
- Please share here so we can all benefit



# Learning Assessment Questions

True or False?

- Advocacy is crucial to protect patients' access to compounded therapies.
- Patient testimonials are powerful tools to engage and educate lawmakers.
- The P3 advocacy website has ready to use tools available for patients and prescribers to become involved.



# Resources

- IACP correspondence
- IACP committees – Communication Committee
- Compounding Today newsletter
- P3rx.org



# Need more information?

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