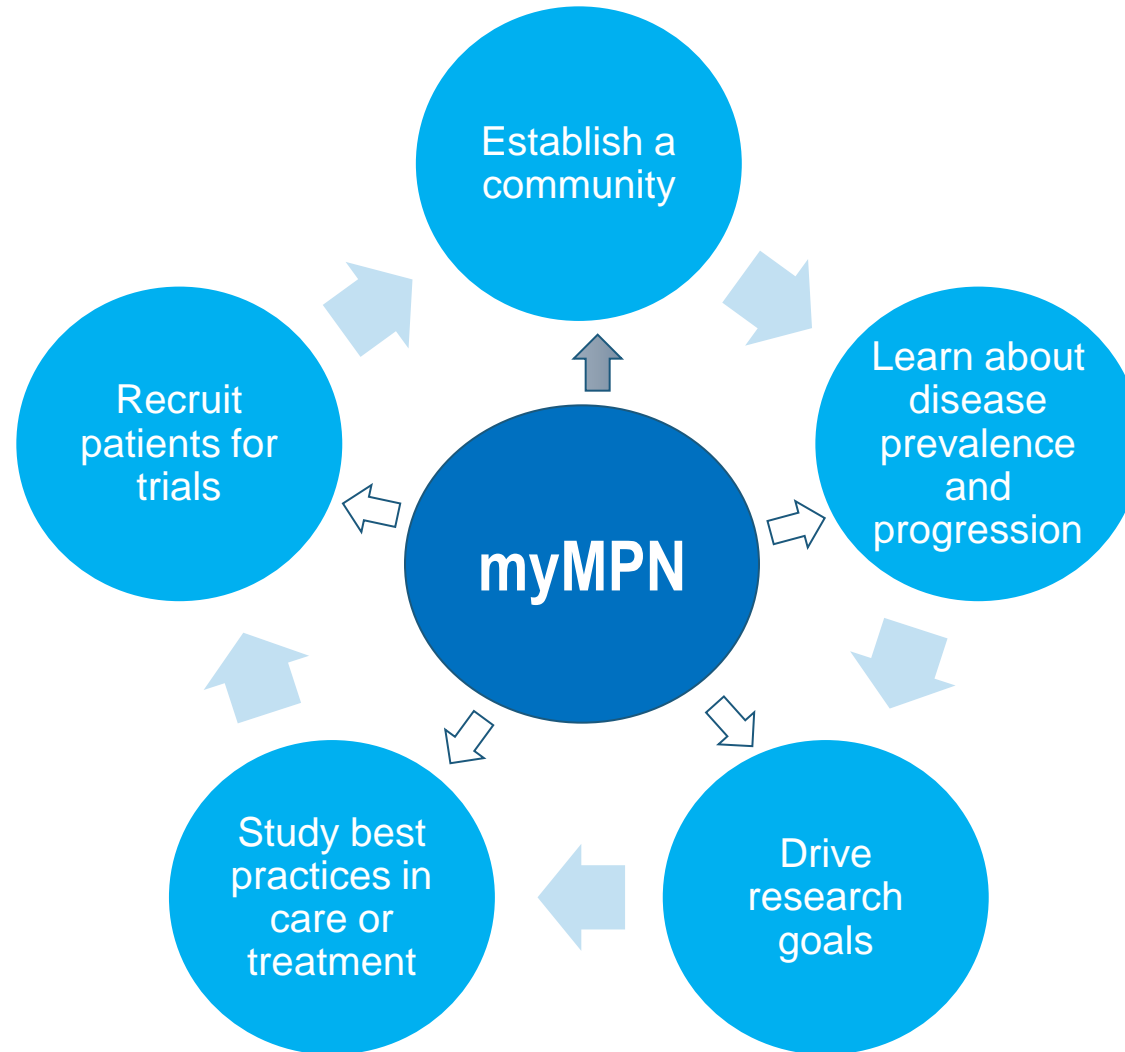




# myMPN: Changing The Prognosis

# MPN Patient Registry

The registry is a powerful tool for patients, researchers, clinicians and industry



# Registry Development

- Internal dialogue at MPNRF about registry began in ~2010

- Steering Committee formed

Robyn Scherber, M.D., M.P.H., OHSU

Brady Stein, M.D., MHS, Northwestern University

Amy Lou Dueck, PhD, Biostatistician, Mayo Clinic

Srdan Verstovsek, M.D., PhD, MD Anderson Houston

Ruben Mesa, M.D., Mayo Clinic, Scottsdale

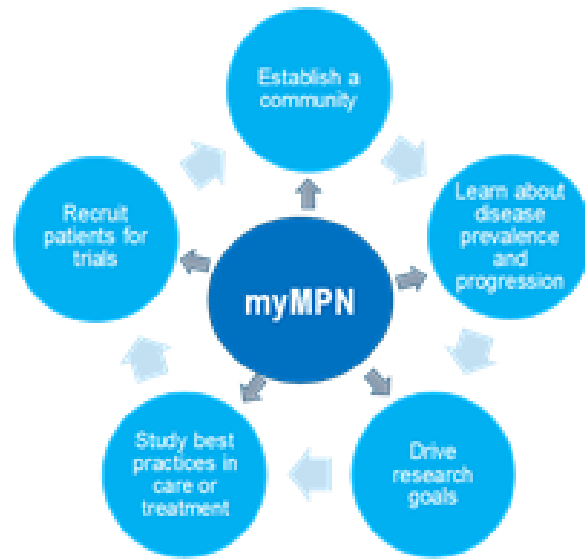
Holly Geyer, M.D., Mayo Clinic

John Mascarenas, M.D., Mt. Sinai

Claire Harrison, M.D. Guy's and St. Thomas' Hospital London

- Reached out to peers who have registry – best practices, pitfalls and successes
- Comparison of features and benefits of various registry platforms (NORD, Genetic Alliance, Patient Crossroads)

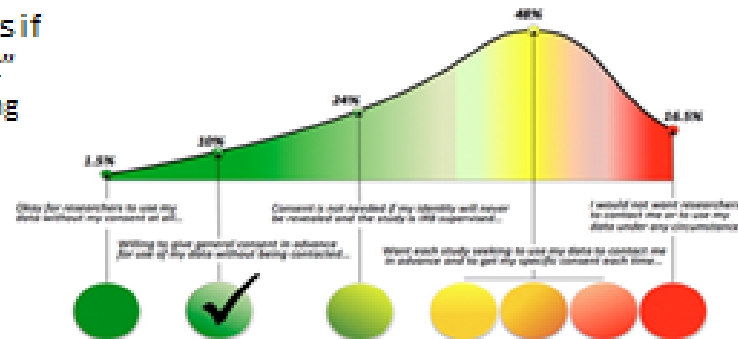
# myMPN



myMPN will allow each patient to determine how much or how little information is shared with the research and drug development community. It puts the power in the MPN patients' hands to drive the research and build a stronger MPN community!

The placement of the checkmarks indicates this guide's starting point in weighing the benefits and risks of consent for Access, and concerns for Privacy of health related information in the context of advancing research into the condition about which they are most knowledgeable.

"The only way I will participate in the registry is if my doctor tells me to do it"  
 – quote from patient during PR discovery session



- 40% of FasterCures survey respondents cite that the primary purpose of their registry at inception was to understand the natural history of the disease

## Progression

## myMPN IMPACT

Jak2 vs CalR - compare and contrast symptoms and progression

Jakafi - is it right for me? How is it working for others like me?

- The number ONE challenge reported by over half of the respondents was attracting participants

## Participation

What are the unmet needs in research? How can we address them?

Does anyone else have my symptoms?

- Genetic Alliance's "Platform for Engaging Everyone Responsibly" collects information from many but MPNRF and patients determine how the data is used

## PEER

How does the timing of certain therapy regimens affect outcomes?

What homeopathic remedies help certain symptoms?

# myMPN in process

Platform selected was PEER from Genetic Alliance

- fully customizable privacy controls
- GA mission consistent with MPNRF



A screenshot of a web browser showing the myMPN website. The browser tabs include "Google Contacts pr...", "Contact Us - FD/M...", "Private Access Admin P...", "Pancreatic Cancer ...", "Private Access Ad...", and "Private...". The address bar shows "lget2.peerplatform.org/demoportal/749#/loginHome". The website content includes a header with the text "LET'S CHANGE YOUR PROGNOSIS" and a main section with the text "SHARE... Answer as many questions as you would like, and control how and with whom that information is shared. CONNECT... Find out how you compare to others, and let support and helpful resources come to you. DISCOVER... If you wish, let researchers access your information to help spark innovation for all." Below this is a large red banner with the text "MPN RESEARCH FOUNDATION CHANGE YOUR PROGNOSIS". To the right of the banner is a section titled "It's Easy as 1, 2, 3" with two buttons: "1 Register (or sign in) Start Now!" and "2 Enter Health Information". Below the banner is a section titled "Respecting Your Wishes is Our Priority" with a "PRIVACY ASSURED with PrivateAccess" logo. At the bottom right, there is a form with the text "MY DOCTOR OR DISEASE ADVOCACY GROUP RECOMMENDED THIS SERVICE AND PROVIDED ME WITH A REFERRAL CODE:" and a "Submit" button. The footer includes "Privacy Policy Terms of Service Give Feedback" and "© 2013-2016 Genetic Alliance, Inc. All rights reserved."



# myMPN Goals 2016-2019

- Target patient profiles

2017

150-300

2018

300-1,500

2019

1,500-6,000

- 2016 – Q4 beta testing, survey upload, data review, develop policies for data access with steering committee, IRB approval
- 2017 - focus on increasing participation through outreach to peer groups, centers of excellence, industry meetings, demonstrating value through periodic data summaries, launch mobile access to the registry
- 2018/2019 - Rollout of new features possibly including EMR upload, additional languages, exploration of tissue banking, etc



# Thank you!