# National PKU Alliance Peer/Pathways Mentoring Program

A Roadmap for How to Establish a World Class Mentoring Program for Adults Affected by PKU and Allied Disorders

*Karen Casey*

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## Summary

An opportunity exists to transform the vision and direction of the National PKU Alliance Peer/Pathways mentoring program. This paper reviews industry leading mentoring programs to analyze best practices in order to identify specific changes to make in the vision, goals and structure of NPKUA's program.

One of the most profound findings of the cross-industry analysis is the importance of opening more effective and efficient communication channels to reach the target community.  A primary recommendation of this research is to first reset the goals and vision of the program in a manner that focuses on the target population. The recommended second step is to then use the foundational vision as a way to inform a more effective program execution plan. The recommendations for which best practices to leverage, combined with practical budget, resource and time constraints together would define the third, program execution schedule development step, aligned with resources to write a template for program success.

## History: Initial Structure and Results

In the fall of 2020, the National PKU Alliance (NPKUA) initiated a mentoring program with the primary goal of helping adults find resources to return to diet. The program consisted of a cohort of volunteers selected from about 65 applications. The training process was a multi-day weekend event using Zoom platform where each participant relayed their own personal story and journey.

The mentors were divided into two separate categories:
- Peer Mentors – consisting of adults affected with PKU
- Pathways Mentors – consisting of adult family members or caregivers of those effected by PKU

After the initial training, the NKPKUA advertised via social media the opportunity for mentees to connect with a mentor. The NPKUA program manager would pair mentees with mentors, schedule monthly meetings with the team of mentees and subject matter experts to discuss success, challenges and also to provide a forum for ongoing training.

## Feedback: Program Activities

In general, positive results were reported in at least half of the mentor/mentee matches. However, several general themes emerged regarding programing activities:
- Challenges connecting with mentees: this ranged from not finding interested candidates, or challenges associated with connections and communications. Specific examples range from not being able to connect by phone, text or email to "disappearing" mentees.
- Challenges with the Qooper App: these issues include difficulty using the App, utility/stability of the App and general reports the App was a barrier to communication.
- Time zone and schedule difficulty planning regular monthly mentoring meetings

One program observer noted that although there were regularly monthly "touch point" meetings with the mentee team – overall the program would benefit from more structured approach to meet the community needs.

After the first year of program activities, the NPKU enlisted the help of Kendra Bjorkaer, a private practice neuropsychologist to improve the training content for the mentors. The original mentor project manager left the NPKUA and in the last three months, the NPKUA Executive Director role changed from Christine Brown to Lisa Milberg. These events, together, open the door for re-envisioning the goals of mentoring program and provide the opportunity to pivot the program in new ways to ensure maximal impact for the community.

## Cross Industry Best Practices: Insight for Future Program Design

There are a significant number of industry best practices and a wealth of scientific research that can be used as sources to find optimal methods for developing and managing a mentoring program. Each example programs provides a model that can be applied and/or tailored to fit the specific needs of the NPKUA community.

A tremendous amount of medical research points to the benefits of a mentoring program, and how networking directly improves overall health outcomes and care experiences. All of these sources of best practices can help guide future plans for the NPKUA program. A description of four relevant model programs is provided below; with a quick summary recommendation of which aspects the NPKUA should adopt.

1. Boeing Aerospace has a long standing, very mature mentoring program that is considered "best in class for the aerospace industry". Their program combines formal training, structured matching/meeting/goal setting with ongoing measures and monitoring. While some of these practices exceed what is needed in a health care mentoring program – some of the structure can easily be borrowed for NPKUA. A striking excerpt from the Boeing program can be used to set the tone of a re-envisioned mentoring program.

   *"Past research tells us while mentors are overwhelmingly satisfied with mentoring programs, <u>mentees often are not</u>. And that defeats the whole purpose. Many companies struggle with mentoring programs, but Boeing's incorporation of tools and metrics, and taking advantage of best practices, will put us among leading programs and create the most return on <u>participants' investment of time and information sharing</u>."*

   NPKUA Characteristics to Harvest:
   - Desire to be best in industry
   - Awareness/reminder to focus on mentee outcomes as the primary goal
   - Tools and metrics – tailored for healthcare
   - Formal training for mentors

2. Cleveland Clinic 4th Angel Cancer Care was started by Scott Hamilton based on his view that during his care he required support from four angels: first his doctor, second his nurse, third

his family/friends and fourth a peer mentor who has lived through the process, https://4thangel.ccf.org/.

*"The Cleveland Clinic 4th Angel Mentoring Program is an <u>innovative, interactive</u> approach to cancer support in which patients and caregivers are matched with trained volunteer mentors with similar age and cancer experiences. The program is a national, <u>free service</u> that emphasizes one-on-one contact to best empower caregivers and patients with knowledge, awareness, hope and a helping hand."*

The <u>four cornerstones</u> of the program, as shown on the homepage of the website, are clear, easy to understand objectives that motivate potential mentees to join.

a. Mission – To provide personalized peer support empowering those affected by cancer and its treatment.
b. Support - One-on-one support with a trained volunteer mentor through online chat, phone or via email.
c. Firsthand Answers - 4th Angel mentors are empathetic and have firsthand answers to all the hard-to-ask questions.
d. Personal Experiences - Your 4th Angel mentor will share helpful and positive strategies learned from his or her own experience.

This approach is an easy pattern that the NPKUA program can use.



**OUR MISSION**

To provide personalized peer support empowering those affected by cancer and its treatment.

**SUPPORT**

One-on-one support with a trained volunteer mentor through online chat, phone or via email.

**FIRSTHAND ANSWERS**

4th Angel mentors are empathetic and have firsthand answers to all the hard-to-ask questions.

**PERSONAL EXPERIENCES**

Your 4th Angel mentor will share helpful and positive strategies learned from his or her own experience.

Another aspect of the program are Testimonials, shown on the website:

**QUOTES FROM OUR MEMBERS**



What a positive experience. My match is a wonderful person and plans on calling me as his treatment progresses. I actually got cold chills from speaking with him. Being able to help someone is a tremendous feeling.

- Mark, 4th Angel Patient Mentor

NPKUA Characteristics to Harvest:
- Highly positive and motivational language (marketing elegance)
- Theme of help, support, encouragement
- Four simple program cornerstones
- Well defined mission statement
- Underscore the service is free
- Simple entry point to support
- Patient focused testimonials

3. Sharsheret is an organization that provides support for health care needs to women in the Jewish breast and ovarian cancer community https://sharsheret.org/?gclid=Cj0KCQjwl92XBhC7ARIsAHLl9anBno72jeOqRSMcH3-OQn-MAw20JlYkbEpE8zX-CpKXmKqTzlJKzTEaAjqcEALw_wcB

    *Our Peer Support Network connects women newly diagnosed or at high risk of developing breast cancer or ovarian cancer one-on-one with others who share similar diagnoses and experiences. You can also share your own experience by becoming a Sharsheret "Link," a peer supporter, and enjoy the rewarding experience of supporting other women across the country. Our confidential "Links" connect over the phone and through email and offer invaluable friendship and support.*

    *Sharsheret does not make medical referrals or endorse or promote any specific medication, treatment, product, or service.*

    NPKUA Characteristics to Harvest:
    - Unambiguous medical disclaimer
    - Easy connection process
    - Theme of friendship and support
    - Focus on personalized "shared" experiences – engaging videos
    - Geographic map – link resources to location
    - More "Network" focused than point to point mentoring
    - Peer Support – anyone can sign up – low barrier to entry

    NOTE: Lisa – If you know your counterpart at this organization, we should reach out to find out how the program is managed, organized, staffed and funded internally. I found their financial report – they are about an $8-$10M organization - annually.

4. Rare Disease Mentoring Programs -There are many technical papers in the medical literature about the value of peer mentoring, networking and family support programs. There is a direct association between engagement in support programs and measurable positive health outcomes  https://pubmed.ncbi.nlm.nih.gov/25231828/.

    *Shared experience was perceived central to successful peer support and was a catalyst for other elements of support, enabling parents to (i) learn from the experience of others; (ii) speak freely in a safe and non-judgmental environment; and (iii) receive support and encouragement from their befriender. These elements underpinned perceived outcomes for*

*both parents providing and receiving support. Outcomes for parents receiving support centered on emotional stability, personal growth and reduced isolation.*

NPKUA Characteristics to Harvest:
- Link between support program and improved emotional stability
- Safe space concept – as a way to promote the program for new members
- Desire to improve outcomes – not just diet related

## Way Forward Program Design: Leveraging Solutions from World Class Programs

## Recommended Vision and Goals

Establish a vision and direction for the program, drawing from common characteristics of world class programs. Envision what a future state of the program looks like based on the examples above.

1. Accelerate and diversify methods to find then connect mentees into the network or resources, and to mentors – Make this the primary focus of the program, over all other aspects
2. Improve External Communication - Create a new "window" into the program
   1. Theme of friendly, open, judgement free support (NOTE: This is personified in KENDRA!)
   2. Brand a new approach associated with connecting to mentees
   3. Marketing – establish new outreach methods/sources: Website, Video's,
   4. Ease entry into the Program – "click here to email us"
   5. Streamline, improve coordination and follow through – consider modern methods to form a network vs point to point
   6. Identify community that is being served & how
   7. Create a simple, positive, supportive message (of hope)
3. Create or Enhance Program Management – Establish the NPKUA philosophy for program management <NOTE: Qualified author does not have much insight into internal management>
   1. Roles/Responsibilities
   2. Metrics
   3. Program Plans and Artifacts
4. Create multiple avenues for Mentor/Mentee Connections and Collaboration
   1. Shared Experience Videos
   2. Goal Setting tools
   3. Formal and informal meeting/communication methods
   4. Non-human in the loop interaction methods and resources – self serve resources
   5. Resource spanning a diversity of needs: emotional, science, insurance, affiliates, health care, technology
5. Create simple, lightweight, automated monitoring, feedback loop
6. Create a pathway to highlight successes, testimonials, community give back

# Program Development Plan

Ideally, we would lay this into a schedule with named resources and committed milestone dates. However, I did not go that far because discussion is needed on the vision, alignment, resources and budget. This can be tailored down to fit a more specific budget and timeline. Below is a general plan that could be used as a guideline to roll out the new project.

1. "Light" Data Collection on Program to Date – need a few additional facts related to what has and has not worked in the past.
    a. Initial Number of Mentors vs. Number currently active
    b. Total number of Mentees gained in program – any trends for enrollment to measure effeteness of COMMs
    c. Quick Survey of Program Effectiveness for Mentors
        i. Number of mentees
        ii. Average number of interactions
        iii. Average period of time for engagement (few weeks/months etc)
        iv. Conclusion of engagement – closure description (goal met, lost contact, resources provided)
        NOTE: This can also be a good source to capture Testimonials
    d. Quick Survey of Mentees (sample size)
        i. When joined
        ii. How did you hear of program
        iii. Expectation (personal interaction, resources, questions to answer)
        iv. Close out (goal reached, lost contact, resources provided)
        NOTE: This can also be a good source to capture Testimonials
2. Simple Program Management
    a. Define Roles, Responsibilities, Expectations Required for the Program
        i. Project Manager/Coordinator
        ii. Mentors
        iii. Trainers/Subject Matter Experts
        iv. Other NPKUA staff
    b. Establish total project budget and available resource pool for marketing
        i. Need sponsorship through medical solution providers (formula, food, Biomarin, Homology, etc.) specifically to fuel the network portion
    c. Hire, name, set expectations for program roles
    d. Establish internal and external communication expectations
3. Onboarding Mentees and Mentors – Establish a goal to create a network balanced with the service of formal point to point training/coaching
        i. Orientation
        ii. Training
        iii. Expectations
4. Open Door for Mentees – Self Service Resources
        i. Open the program to anyone with experiences – Mentors
        ii. However, tier the mentors to form effective matches

   iii. Create easy network to tap shared experiences – e.g., a video a highlight of "My Story" with a contact us now link
    1. Suzanne – Adult that was encouraged to go off diet – understand difficulty but knows the right choice change her life
    2. KC Video: Mom for 18 years of CPKU, early on had very difficult clinical experiences, poor choice of language w/ providers, educational background in nutrition and dietetics
  iv. Networks
  v. Easy access
  vi. Geography
  vii. Affiliates
  viii. Medical community
 b. Structured Matching
  i. Mentoring Agreement
  ii. Goal Setting
 c. Regular Evaluations
  i. Entry/Exit Survey
 d. Link to broader Community
  i. Tie back into other programs and events (Advocacy, Education, Fundraising)
  ii. Link to Affiliate organizations

# Conclusions

A it important to note that this author did not have insight into the "internal" objectives, plans and budget resources used to establish the original program. However, the program did feel a bit "ad hoc" from an outside perspective. Investing in a small amount of time to understand key metrics like the total number of program participants, in comparison to the budget is critical.

Second, while the current program has some strengths a wholesale change in approach may be necessary. Tactics such as the Qooper application and bi-weekly meetings to facilitate communication may need to be revaluated. Instead, resources could be directed towards dividing up some of the recommendations listed above and asking individual volunteers to tackle items listed in the last two sections of this paper and come up with a specific plan. For example – ask for a volunteer to set up a survey of past and present participant – mentor/mentee. The data from simple phone calls with three of four questions would be insightful.

Another easy area to break off a sub-project tasks would be in the area of communication and harvesting new entrants into the programs – developing "experience" or "testimonial" videos.

A third area to focus short term resources would be in branding the program. This could be tied into overall organizational brand and goals. In short, there are ways to move forward in a different direction that can be done in a short time period with limited resources.

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