

# Advocacy: Why It Still Matters

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# Overview

- Quick Review: How to develop an effective advocacy plan
- Your role
- PNH Association's role



# How to Develop an Effective Advocacy Plan

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- Key message development
- Development of your tools
- Development of your one 'ask'



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# Key Message Development

## *Identification...*

- Requires that you be able to take an array of information and distill it down to its simplest form
- Requires that you separate fact from fiction
- When advocating on behalf of a group, consensus on the issues is required



# Key Message Development

## *Framing...*

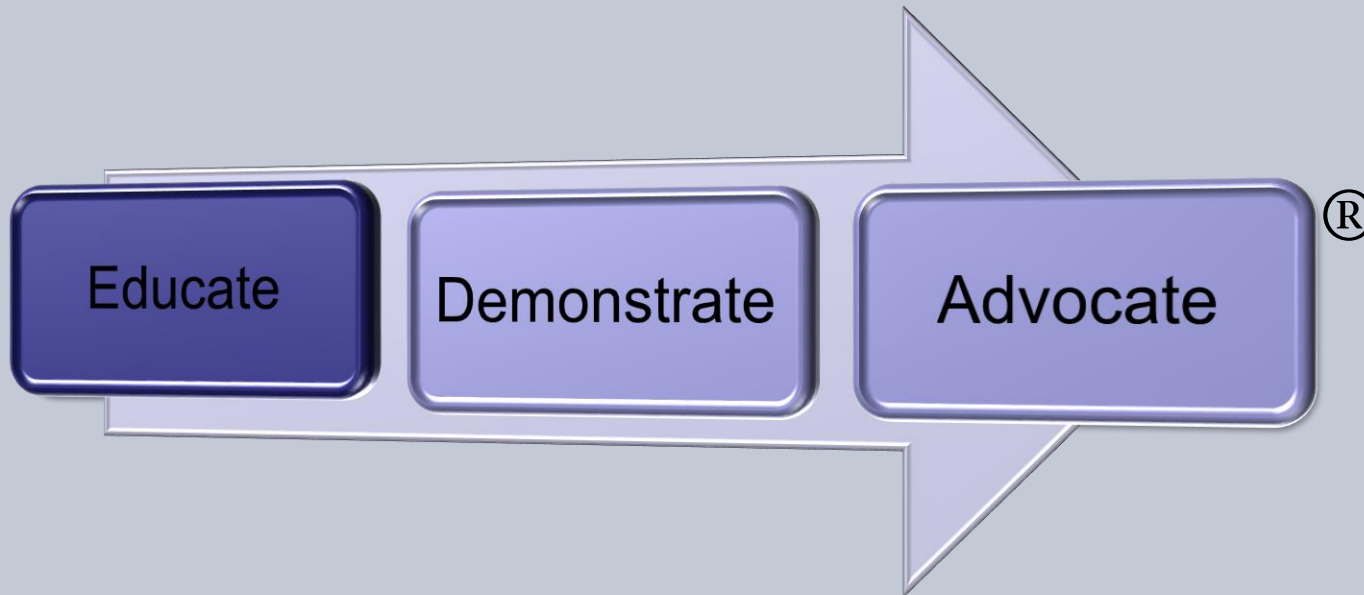
- Develop 3 key messages that explain the salient points of your issues in simple language
- Each key message should be 25 words or less
- Must always be clear, compelling, concise and consistent
- Practice presenting your key messages to someone with no knowledge of your issues



# Advocacy Tools

The means of delivering the messages...

As a process, three steps must be followed regardless of the tool being utilized to get to advocacy stage:



# Your One 'Ask'

*The objective or goal of the plan...*

- **ONE** – because you are going to ask for what you need, not a list of what you want
- Requires one to make choices and potentially reach a consensus (just as it does when developing your 3 key messages)
- Sometimes opportunities will present themselves that will make the 'ask' very timely



# Your Role

- To advocate for yourself (access to current treatments, new treatments)
- To advocate for the PNH Association (new treatments, other issues)
- It is critical that you (and your caregivers) know how and when to advocate on your behalf
- As is said “the squeaky wheel gets the grease”
- So whether it’s advocating to your physician about your personal care or your provincial member of parliament about a broader health care issue affecting you and others in your community, the need to engage is important





# PNH Association's Role

- To ensure that existing treatments remain accessible to you
- To ensure that people not currently on treatment who could benefit, get access in a timely manner
- To ensure that any new treatments are made accessible as quickly as possible
- To provide you with the resources needed to advocate for your care on a personal level and join with others in a collective effort to ensure that the interests of PNH patients and their families are represented to gov'ts



# Advocacy Solutions®

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