National Jewish Health
Idiopathic Pulmonary Fibrosis Survey

1. [PATIENTS INTRODUCTION]

   National Jewish Health is developing educational tools and resources to facilitate communication between IPF patients and their providers. We are conducting a survey that shouldn't take more than five minutes of your time, and your insights will help us develop resources that we hope you will find helpful in managing IPF.

2. When were you diagnosed with IPF? (dropdown)

   2017
   2016
   2015
   2014
   2013
   2012
   2011
   2010
   Earlier than 2010
   I have not been diagnosed with IPF

3. Please indicate the THREE most important educational topics you would like to know more about (select three):

   How doctors make an IPF diagnosis...............❑
   What tests doctors use with IPF patients ....❑
   How doctors follow IPF patients over time ....❑
   Medications for IPF (options and their risks and benefits)❑
   Supplemental oxygen❑
   Why and how to exercise with IPF ....❑
   Pulmonary rehabilitation ....❑
   Emotional health❑
   Disease progression and what to expect❑
   Acute exacerbations of IPF❑
   When to contact your medical provider ❑
   Other medical conditions associated with IPF❑
   How acid reflux may be related to IPF ....❑
   Lung transplantation options❑
   End of life care❑
   Research on IPF ....❑
   Other (Please Specify)......................................❑

4. What are the THREE most important educational topics you would like to have available for your caregivers (family, friends)?

   How doctors make an IPF diagnosis...............❑
   What tests doctors use with IPF patients ....❑
   How doctors follow IPF patients over time ....❑

Medications for IPF (options and their risks and benefits)❑
Supplemental oxygen❑
Why and how to exercise with IPF ....❑
Pulmonary rehabilitation ....❑
Emotional health❑
Disease progression and what to expect❑
Acute exacerbations of IPF❑
When to contact your medical provider ❑
Other medical conditions associated with IPF❑
How acid reflux may be related to IPF ....❑
Lung transplantation options❑
End of life care❑
Research on IPF ....❑
Other (Please Specify)......................................❑

5. We are building a website to act as a hub, or starting point, for users to find out more information about IPF. We will also use the website to develop other educational materials in different formats. Are there any topics not indicated in this survey that you feel would be important to include? (open ended)

6. In terms of providing YOU with this information, how would you rank each of the following methods, with 1 representing the most useful method and 4 being the least useful? (ranking)

Printed materials, such as brochures __
Website__
Videos (on a website)__
Live education classes__

7. What do you feel is your biggest challenge related to living with IPF? (open ended)

8. Is there anything else you would like to share to help us as we develop resources for IPF patients and their healthcare providers? (open ended)