Questions to ask your doctor about Pulmonary Fibrosis

DISCLAIMER: Please note I am not a medical professional. I spent 6 years as caregiver for my mom, until her passing in 2009. I have since been a PF Advocate for Patients & Families, as well as moderator & owner of the Breathe Support Network of Groups. Information provided is from personal experience, combined with years of learning through interaction with patients, other caregivers, & medical professionals in the field of PF/IPF.

The following is a list of some questions you might ask your doctor when looking at a pulmonary fibrosis diagnosis. This is not an exhaustive list. There could be many others you may need the answer to.

After each question is some information about what you might expect to hear from a doctor who is highly knowledgeable in diagnosis and treatment of those with PF/IPF. Again, this is not exhaustive, but it gives you some things to expect.

1. **What is Pulmonary Fibrosis?**

   Pulmonary Fibrosis (PF) is a thickening of the lung tissue, called "scarring" or "fibrosis". It causes the lungs to not be able to perform their important job of filtering the carbon dioxide out of the blood and exchange it for oxygen.

2. **What causes Pulmonary Fibrosis?**

   There are many causes of PF, as well as PF with "no known cause", called Idiopathic Pulmonary Fibrosis, or IPF. Some of the known causes are:

   Autoimmune disorders
   Some medications (chemo treatments, some antibiotics)
   Exposures (asbestos, farm dust, birds, and others)
   Chronic pneumonia
   Heredity (approximately 15% of the PF cases)
   Others

3. **What is the basic testing to confirm a Pulmonary Fibrosis diagnosis?**

   Regardless of what brings a patient into the clinic for a PF diagnosis, the basic tests that one should expect are:

   HRCT (high resolution lung CT) – This is different from a regular CT or a CT with contrast. A HRCT is better at detecting the scarring spread and pattern on the lungs. Standard X-Ray is not the best diagnostic scan for confirming PF as it will often miss scarring on the lungs, especially in the earlier stages of the disease.

   PFTs (Pulmonary Function Tests) – These are the "breathing tests" done in a Pulmonary Function Lab. Patients will inhale and exhale into a special mouthpiece and tube that is connected to a computer. Various breathing patterns will be measured during a series of tests. The results of the PFTs will help to determine if the patient has PF. DLCO (Diffusing Capacity) should always be checked when diagnosis and following up on patients with PF/IPF.

6MW test (6 minute walk test) – This is what is sounds like. The patient is taken for a walk, usually up and down a long hallway (about 100 feet long), for 6 minutes. The test is to determine how far a patient can walk at a brisk pace on a flat surface over the course of the 6 minutes, while taking measurements of their oxygen saturation at various intervals along the way – WHILE ACTIVE. (This makes a big difference in diagnosing PF, because the norm with PF is that a patient's oxygen saturation may quickly normalize as soon as activity stops.) Typical for PF would be to see a decline in oxygen saturation while active. As PF progresses, patients will see this decline even while fully at rest. Patients may also see a decline in oxygen saturation while they sleep before the see it any other time. NOTE: If you are waking up extremely tired or yawn a lot, and you are not yet using supplemental oxygen, ask your doctor to order a test of your oxygen saturation while you sleep.

Breath Sounds – Your doctor should spend significant time listening to your breath sounds with his/her stethoscope. More than the cursory couple of seconds. The doctor should also listen to both the top and bottom of your lungs and listen to both lungs. PF makes a specific "sound", like that of Velcro separating. They often refer to it as "crackling".

Physical Examination – A good physical examination by your doctor should happen.

Medical History – Complete with exposures one might have had in the past/present, family history of lung disease, etc.

Arterial Blood Gas – This is a blood draw from the artery in your wrist to check the level of carbon dioxide in your blood after it has gone through the gas exchange in the lungs.

Other Blood Tests – Blood tests to check for other causes of PF, such as autoimmune disorders.

These are the minimum that should be done in confirming a PF diagnosis. If these tests cannot confirm a PF diagnosis (or rule it out completely), more invasive tests, such as a lung biopsy of some kind may be needed. Lung biopsies are not done as the norm any longer due to the risk of complications (including death) and also because scanning technology is so much better than in the past and often the scan (combined with the other testing) can confirm a PF diagnosis.

4. Is Pulmonary Fibrosis genetic?

Sometimes, yes. In about 15% of the cases, PF is genetic. This is called Familial Pulmonary Fibrosis or FPF. However, just because one may have a genetic factor does not mean they will have PF. There are various FPF studies being done around the world.

5. Is Pulmonary Fibrosis contagious?

No. Pulmonary Fibrosis is not contagious.

6. **Is Pulmonary Fibrosis treatable?**

Treatment depends on the form of PF you have been diagnosed with.

Idiopathic Pulmonary Fibrosis (IPF) is one form of PF and is the most prevalent. Unfortunately, it tends to be the most difficult in terms of treatment and can often be the fastest progressing. As of the fall of 2014, in the United States, there were 2 drugs approved by the FDA to treat IPF. The drugs – OFEV (manufactured by Boehringer Ingelheim) and Esbriet (manufactured by Genentech) – only slow the progression of IPF. They don't work for all patients, but for a large percentage. They are not a cure. They do not stop progression of the fibrosis entirely. The two drugs do the same thing, but in different ways, so it is important if you are trying one that you keep in good communication with your doctor if it isn't working for you. You might find that the other works better for you. Patients have different experiences with these two drugs. There are also prescribing protocols for these drugs. They are only approved for those with "mild to moderate IPF". This is currently defined as a patient with a DLCO (Diffusing Capacity) greater than or equal to 30% and an FVC (Forced Vital Capacity) greater than or equal to 50%. Prescribing to patients with lower values than that or to patients with a form of PF that is something other than IPF would be considered an "off label" prescription and may not be covered by insurance.

NOTE: One or both of these drugs may be available in other countries. If you are not from the United States, talk to your doctor about these drugs. Esbriet has been available in many other countries around the world for a lot longer than it has been available in the United States.

Some other forms of PF are treatable in the sense that the "cause" is treated in hopes of slowing or stopping the progression of the fibrosis. For instance, if a patient is diagnosed with a form of PF caused by an autoimmune disorder (like Rheumatoid Arthritis) the autoimmune disorder is treated with the goal being able to control both the autoimmune disorder as well as slow or stop the progression of the fibrosis taking place.

In some cases the treatment is to remove the cause. If the cause is environmental for example, if the exposure is removed, this may slow or stop the progression of the fibrosis.

NOTE: Sometimes patients will see a slowing or halt of the progression of their fibrosis after the exposure is removed. However, it may be the case that after some period of time, they see the fibrosis start to progress or progress faster again.

7. **Is there a cure for Pulmonary Fibrosis?**

No. There is no cure for Pulmonary Fibrosis.

8. **How is my disease going to progress?**

Not all forms of PF are progressive and some are more progressive than others.

Quite literally, PULMONARY = LUNG and FIBROSIS = SCARRING. It is possible to have scarring of the lungs that is NOT progressive. For instance one can contract pneumonia and have some residual scarring of the lung tissue withOUT it becoming "progressive pulmonary fibrosis".

Progressive PF progresses at a different rate and even in a different pattern for various patients. Sometimes the fibrosis starts at the base of the lungs and moves upward. Sometimes it may start at the top of the lungs and move down through the lung tissue.

PF may progress at a slow and steady rate or it may progress at a rapid and steady rate or it may progress like a stair step – a rapid decline followed by stability followed by a rapid decline followed by more stability.

9. Can I have more than one form of PF?

Yes. It is possible to have both IPF and some other form of PF.

10. What can I do to keep myself otherwise healthy? (vitamin supplements, immunizations)

It is important to stay as healthy as possible. PF WILL take a toll on your heart as well as other parts of your body. Having a healthy diet, exercise (even if it's just walking), taking ones vitamins regularly, and getting regular immunizations for the flu (influenza) and pneumonia is important (unless there's a medical reason one shouldn't have immunizations).

It is also important to see a cardiologist for a baseline heart evaluation to check cardiac health. A baseline exam should include an echocardiogram (ultrasound of the heart and non-invasive). Ongoing care should continue (with an exam every 6 months to a year, sooner if one starts to experience problems).

Lastly, it is also important to have a good relationship with your GP and get treatment right away if you start experiencing any sort of respiratory infection. Anything from the common cold to pneumonia can be dangerous and fatal quickly in someone with lung disease.

11. How do I get enrolled in Pulmonary Rehab?

Pulmonary Rehabilitation is a monitored exercise program that most everyone with PF/IPF should be referred to. Your doctor has to make a referral for you to attend Pulmonary Rehab. Even many with limited mobility should get into a Pulmonary Rehab program. Many newly diagnosed PF/IPF patients are limited due to weakened muscles from having PF and not getting enough exercise.

Pulmonary Rehab can help strengthen the body (especially the large muscles) and help the body to use oxygen more efficiently, making a PF patient feel better and be able to be more active and independent.

12. How often should I get a pulmonary check up? (high resolution CT, full round of PFTs, 6 minute walk test, physical exam, etc)

You should get a pulmonary check up every 6 months. PFTs, 6mw test, and physical exam should be done at every check up. An updated HRCT should be done if there is a significant change in PFT and/or 6mw test results or if new symptoms arise.

New symptoms or worsening of one's breathing should signal a pulmonary check up as well.

13. What do the numbers on the Pulmonary Function Tests (PFTs) mean? There are so many numbers, are there any specific ones that should matter to me?

There are many different test results from PFTs. The ones typically used when tracking progression of PF/IPF are:

DLCO (Diffusing Capacity) – DLCO gives an idea of how well the lungs are handling the gas exchange, exchanging carbon dioxide for oxygen in the blood. Normal DLCO for someone with healthy lungs is 80%. This number will decrease as fibrosis spreads.

FVC (Forced Vital Capacity) – FVC is a measure of how much air a patient can forcibly exhale after a deep inhalation.

FEV1 (Forced Expiratory Volume) – FEV1 is a measure of how much air a patient can forcibly exhale in 1 second.

TLC (sometimes called TLV – Total Lung Capacity or Volume) – TLC is a measure of the volume in the lungs after a maximum inflation.

**FVC or FEV1 are typically used in conjunction with the term "lung function."*

14. Are there other doctors I should be seeing for testing? (cardiologist, gastroenterologist, etc)

Yes. Every PF/IPF patient should get established with a good cardiologist. The heart and lungs work together so over time, as the lung disease progresses, the heart will take on a heavier load. This will weaken the heart. There are things that can be done (medications, etc) to help the heart perform more efficiently.

Every PF/IPF patient should get established with a good gastroenterologist for testing for GERD (acid reflux). GERD is known to exacerbate (and possibly cause) PF/IPF as the stomach acid backs up the esophagus and can spill over into the lungs, causing further damage.

There are other specialists one may see based on their cause of PF. For instance, if you have PF caused by an autoimmune disease, you would want to see a rheumatologist regularly.

15. Are there other problems that Pulmonary Fibrosis can cause down the road that I need to be aware of? (Pulmonary Hypertension, heart problems, etc)?

Yes. A common side effect of PF/IPF is Pulmonary Hypertension. PH is high blood pressure of the lungs and is secondary to PF in this case. It causes additional shortness of breath as well as problems with the heart. Initial signs of PH can be detected on an echocardiogram. Further testing is required to confirm a PH diagnosis.

Secondary PH is highly resistant to medical treatment. One way to help stave off PH is to make sure to use supplemental oxygen regularly when your oxygen saturation is falling below 90%. The longer you go without that necessary oxygen, the faster secondary PH may become a problem.

PF/IPF also takes a toll on the heart, causing it to work harder, so various heart problems can occur over time. Many are manageable with heart medications. One heart problem that is common in PF/IPF patients is Congestive Heart Failure. CHF can be helped with a diet low in sodium (your doctor may recommend 1,200 mg per day or less of sodium). In CHF, the body will start retaining fluid. Fluid retention typically starts in the extremities and works its way further into the body, eventually ending up with fluid inside the lungs. This is a very dangerous and emergent problem. If you start noticing swelling of the feet and hands, it is important to see a doctor soon to be evaluated for fluid retention. If you notice sudden worsening of shortness of breath, you should go to an emergency room (preferably by ambulance in case of complications along the way). Patients are often put on medications which will help rid the body of excess water. These medications, called "water pills" (one common brand is Lasix) will help rid the body of the fluid through increased urine output. The side effect of these medications is that they also strip the body of potassium. It is important to talk to the doctor about a good prescription potassium supplement while taking these medications. It is nearly impossible to get enough potassium through diet alone when taking these meds. Low potassium mimics a heart attack and can be fatal.

PF/IPF can also cause muscle fatigue, shortness of breath, and problems with short term memory and cognitive ability. All of this is due to low oxygen saturation. When oxygen saturation falls below 90%, it causes the muscles to be oxygen deprived, causing muscle fatigue. Muscle fatigue can make a patient feel as if they are more sick than they really are. Saturation below 90% also causes brain cell death to occur. The first things affected are short term memory and cognitive ability. Unfortunately, these effects are irreversible. While scientists now know that brain cell regeneration is possible, it takes longer for brain cells to regenerate than it does for them to die. The process is much too slow and for someone with ongoing lung disease, they will experience the effects for the remainder of their life. The best way to slow these effects is to use supplemental oxygen when saturation is falling below 90%.

16. If I am on supplemental oxygen, how do I know if I am using enough oxygen? How would I feel if I am not getting enough oxygen?

See the answer to #15 above.

Know that EVERY "body" needs oxygen. Oxygen is not something the body can go without, just as it can not go without water. But it can go without water a lot longer than it can go without oxygen. Your body will not "get used to" less oxygen and it will continue to degrade in performance. Think of oxygen as a prescription medication. If your doctor prescribed insulin because you are a diabetic, you likely would take it as prescribed. This is how you need to think of oxygen. Make sure you are keeping your oxygen saturation from falling below 90%.

17. How do I manage my symptoms? (shortness of breath, weight loss or weight gain, loss of appetite, cough, lung/chest/back pain)

Shortness of breath can be largely managed by the proper use of supplemental oxygen. However, you may find you have some shortness of breath all the time due to your lungs not performing properly.

Weight loss and weight gain need to be managed with diet as much as possible. Many PF/IPF patients experience weight gain, while some experience severe weight loss. This is difficult for anyone. Weight gain can be caused from lack of good exercise but also from steroid medications used in treating PF/IPF. It is important to maintain a diet rich in protein and complex carbohydrates, while cutting back on simple carbohydrates (sugars).

Sugar is more than just "sugar". Foods your body treats as sugar should also be limited. For instance, foods made with enriched white flour are "sugar" to your body. These can cause weight gain, as well as cause inflammation in your body. Reducing these can aid in weight loss as well as decrease inflammation. Decreasing inflammation can be very good for those with PF/IPF.

Exercise is an important factor in maintaining as long as possible with PF/IPF. However, it is important to know what your limits are and not push yourself so much that you cause yourself to become sick. Find that sweet spot where you are getting good exercise (for your stage of the disease) yet not overdoing things.

Cough is common and problematic in those with PF/IPF. Not every patient will experience a bad cough, but a lot will. There are many ways to help with this, from natural remedies to over the count (OTC) cough medication to prescription medication ranging from non-narcotic to narcotic formulas. Some natural remedies are to sip hot water or hot tea, honey (naturally suppresses cough), and fresh pineapple juice. There is an enzyme in fresh pineapple juice that suppresses cough and it has proven to be quite successful for many with "the PF cough". There is also now an OTC pill called Bromelain which contains this enzyme. For any OTC medication, talk to your doctor first as all medications can have side effects and react with other meds you might be taking.

Many with the "the PF cough" eventually end up on something like Morphine. One of the best ways to handle the sedative factor of the drug as well as help "control" cough is to take more frequent small doses rather than a few large doses throughout the 24 hour period. NEVER EXCEED THE 24 HOUR DOSE. Simply break it into more frequent smaller doses. Many have found this helps make it less sedating and also helps stay in front of the cough rather than trying to get it under control when it starts. It's the same concept

as “staying in front of pain”. NOTE: Some doctors will be unwilling to prescribe narcotic cough meds to patients with PF/IPF because it is a sedative and they feel it will suppress respirations. This is unfortunate because this type of drug becomes a necessary staple to those with PF/IPF, especially those in the end stages.

The PF cough can also cause a lot of anxiety for patients and many take an anti-anxiety medication as well. Again, this is another one some doctors are unwilling to prescribe because of it’s sedating quality, but again becomes a necessary staple to many with PF/IPF, especially those in the end stages. When doctors refuse these two classes of drugs to their PF/IPF patients, they are sentencing them to suffering. Have a candid heartfelt conversation with your doctor if this is happening. Advocating for yourself (or your loved one if you are the primary caregiver) is very important in managing this disease.

Lung/chest/back pain are common in those with PF/IPF. First to note… there are no pain receptors in the lungs so it is common to hear medical professionals to say “you aren’t feeling pain because the lungs don’t feel pain”. What is more likely to be the case is that you are experiencing muscle pain due to cough or possibly pain from an inflammation of the pleural sac around the lungs, called pleurisy. The pleura does have pain receptors. It’s common to have this problem, either for no reason at all or due to an infection of the pleura, which often precedes or can come with pneumonia. Not everyone will end up with pleurisy and not everyone with pneumonia will develop it, but when you do, it is incredibly painful and should be treated accordingly.

Chest pain is common as well, especially muscle pain with cough, BUT… any NEW chest pain that has not been diagnosed should be taken seriously and you should seek medical attention immediately. Heart attack is VERY common in PF/IPF patients and you should not ignore this or any cardiac symptoms. Chest pain can also be common in GERD, but again, if it’s new or worsening, don’t ignore it. It is always best with chest pain to err on the side of safety.

18. Can I get a lung transplant?

Possibly. Talk to your doctor about being evaluated for a lung transplant. Both single and double lung transplants are given to those with PF/IPF. A double lung transplant is not necessary to sustain life. Many with single lung transplants do quite well. It is important to note that not everyone will qualify for a transplant due to various factors like age, other co-morbidities, how sick they are with their PF/IPF, etc. It is also important to note that a transplant is NOT a “cure”. Lung transplants come with their own set of issues. Medical follow up is incredibly important and must be taken seriously. Lung transplant patients spend a lot of time at the doctor’s office for tests and procedures following transplant. For those who do well, over time this lessens. Lung transplant patients also take a LOT of medication. Some to ward off rejection. Others to deal with the side effects of those drugs. Lung transplants do not have the best statistics, but remember… statistics are averages and no one is average. There are many patients who have had a lung transplant and survived for more than 5, 10, 15, and even 20 years.

To learn more about lung transplant, join the Breathe Support group called "Pulmonary Fibrosis Lung Transplant Support by Breathe Support". This is a great way to ask questions of those who have been through the process.

Remember that being evaluated sooner rather than later is best. There is a fine line between "too well to transplant" and "too sick to transplant". It is not uncommon for patients who are listed for transplant to suddenly find they are "too sick to transplant" and are taken off the transplant list.

Also note that it is easier to say no in the end (up until the time you enter the operating room) but it is not always easy to request later to be evaluated. There may be procedures that need to be done prior to transplant that you don't have time for. It's better to do the evaluation early on and make your final decision much later.

I can't stress enough how important it is that you know that THIS decision is YOUR decision. This is something that YOU have to undergo. Not your family or your friends. YOU have to be willing and able (emotionally and physically) to take on all that comes with a transplantation. Some patients sail through with very few problems. Others do not. Ultimately, it is YOUR decision.

19. Do you have any literature you can give me to read about Pulmonary Fibrosis?

Your doctor should point you to the online website for the Pulmonary Fibrosis Foundation (PFF) at www.pulmonaryfibrosis.org. If your doctor doesn't know about this, then your doctor may not be your best resource for PF/IPF care. If you feel your doctor is not knowledgeable in PF/IPF diagnosis and treatment, you can look for another on the PFF website as well. Choose *Life with PF* from the main screen, then choose *Find Medical Care*. UNcheck all the options EXCEPT *Care Center Network site*. Enter your state and choose to search for a CCN near you.

CCNs are clinics that have been identified to have medical professionals knowledgeable in PF/IPF diagnosis and treatment, as well as have other things like on site face-to-face support groups, pulmonary rehabilitation, PF/IPF education, and the many other specialties that PF/IPF may need (cardiology, rheumatology, etc).

Other good sources for PF/IPF information are the NIH (National Institutes of Health) website and the ATS (American Thoracic Society) website.

You can also find a "resources" document I put together on all of the Breathe Support Network groups in the FILES section or you can message me directly and I will send it to you.

20. I am on inhalers prescribed by another doctor for my breathing problems. Should I continue using them? What do they do to help me?

You should continue with any medical care you are already receiving unless told otherwise by your doctor. Make sure you let your new doctor/s know what other medications and medical conditions you may have.

21. If I need to see a doctor in between my appointments with you, who should I see?

Your pulmonologist will most likely tell you to see your GP, however some pulmonologists begin regularly seeing their PF/IPF patients instead.

22. If I think I am getting sick (like with the flu or have a cold) what should I do?

Doctors who understand PF/IPF well and understand how quickly even a minor respiratory infection can take hold on the lungs of a PF/IPF patient, will tell you to NOT wait to seek medical attention if you are getting sick.

23. How much involvement will you have in my ongoing medical care?

Your pulmonologist should suggest you see him/her every 6 months to a year (hopefully 6 months) for a re-evaluation. Sooner if you are experiencing new or worsening problems.

24. Are there any local face-to-face support groups available to me?

Hopefully there are, but if not, check the PFF website. Under *Find Medical Care*, check the box that says "*support groups*".

You can also check the ALA (American Lung Association) websites for their Better Breathers Club. Just recently the ALA has started incorporating PF/IPF into their BBC's, which used to be for COPD patients only. NOTE: Because these groups are now mixed with COPD patients and PF/IPF patients, it is important that you understand when having discussions at meetings that COPD and PF/IPF are markedly different diseases and not everything is the same between the two.

25. How should I talk to my family about this and what to expect?

Talking to your family is something that you need to do when you are ready, however I always encourage patients to do it as soon as possible. I hope your doctor encourages this as well.

Progressive PF/IPF is a terminal illness and it is one that can change quickly. Patients can be seemingly fine, maybe not even in need of supplemental oxygen yet, and then suddenly have an acute exacerbation and spiral down, becoming very sick (or worse) quickly. There is no true "staging" with PF/IPF and therefore there is no good way to give a patient an accurate prognosis (like there is with many cancers). PF/IPF can also react differently in each patient. This is why so many doctors use the "statistics" and you may hear or read "You have 3 to 5 years" to live. Statistics are averages and no one is average, but… never trust this disease. It's better to prepare yourself and your loved ones. This preparation comes with not only telling them what is happening to you, but also preparing important paperwork, financial decisions, end of life care and final wishes, etc. These are not easy conversations to have or decisions to make but it is important that others understand the reality of what is happening and it is important that they also know your wishes. As a former caregiver (daughter of a mother with IPF),

I can tell you that I am so grateful she was open and honest with me about what she wanted. I didn't have to try to figure out how to honor her wishes.

One way to help prepare your loved ones is to get them to join either a face-to-face PF/IPF support groups or one of the support groups on the Breathe Support Network. We have a variety of groups and they can find one that fits their needs. This is an excellent way for them to become educated about the disease as well as how it is going to affect you along the way. With PF/IPF being a fairly "invisible" disease, this is especially important. Loved ones don't often realize just how difficult this disease is for patients and what is going on inside the patient's body that they can't see. They often feel "my loved one doesn't look sick therefore they must be making more of this than it truly is".

26. What should I be thinking about wrt palliative care and/or hospice care in the future?

Everyone diagnosed with PF/IPF should be offered at least palliative care. Palliative care is open to all terminal patients, regardless of life expectancy. Palliative care is different from Hospice care. Hospice is typically reserved for patients who are nearing end of life. Some Hospice chapters still require a diagnosis of 6 months or less to live, but many simply meet with patients and do the intake, decide if Hospice is right for them, and if so, enroll them in Hospice. Later, if they live for 6 months or longer, they will reevaluate to see if Hospice is still appropriate. There are PF/IPF patients who have been on Hospice care for years.

Hospice care however requires that patients have given up on life saving treatment. A DNR is required. Medical care is still given for things that are considered "comfort care" and other medical issues such as a respiratory infection, diabetes, thyroid disease, etc. But those listed for transplant and those wishing to have life saving treatment such as CPR, ventilation to assist with breathing in the event of a major medical problem, etc. are not qualified for Hospice care.

For patients still wishing to undergo regular medical treatment, including life saving treatment, Palliative care would be their choice. They will have visits from nurses and will have resources available to them if they have questions about their medical care.

You would need a doctors referral for Palliative or Hospice care.

If you have questions or comments about this document, you can reach me at the contact information below.

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Breathe Support Network
Advocating to provide support for pulmonary fibrosis patients & families

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