

Constant Contact Survey Results

Survey Name: Lung Transplant in PCD

Response Status: Partial & Completed

Filter: None

Jan 07, 2008 12:51:54 PM

1. In the event that you or a loved one with PCD requires a lung transplant or a lobectomy (includes any sort of resection of lung tissue), would you be interested in tissue donation?

	Number of Response(s)	Response Ratio
Yes	56	87%
No	1	1%
Other	3	4%
No Responses	4	6%
Total	64	100%

2. Are you or a loved one with PCD currently listed for transplant or considering a transplant or lobectomy?

	Number of Response(s)	Response Ratio
Yes, listed for transplant	1	1%
Yes, scheduled for lobectomy or resection	0	0%
Yes, considering transplant, but not yet listed	3	4%
Yes, considering lobectomy or resection, but not yet scheduled	2	3%
No	52	81%
Other	2	3%
No Responses	4	6%

Total

64

100%

3 Comment(s)

Too soon for consideration at this time. But has been discussed.

I am seeing a doctor at the local Transplant center. a transplant is still far from my thoughts.

Lobectomy was 53 years ago

3. For any "Yes" answers in question number 2, please provide the names of the lung transplant program(s) you are working with or considering. This information will guide our initial efforts to contact transplant programs.

5 Response(s)

Have not decided

Am currently only considering resection; have only consulted with my pulmonologist and do not know who would perform the procedure should I elect to do it.

St. Joseph's Hospital (CHW) Phoenix

Toronto, Montreal

Dr. Cesar Keller, M.D., Mayo Clinic Transplant Program, Jacksonville, FL

Dr. Scott Palmer, M.D., Duke Medical Center Transplant Program, Durham, NC

4. Please use this space for questions, comments or suggestions for the PCD Tissue Bank Program.

9 Response(s)

When I die you can have them.

What are the chances of survival after lung transplant these days?

How will cloning assist with lung transplant programs? and how close are we to this major step in medical technology?

I wish it were common knowledge about the tissue donation. My lung specialist has never suggested it at all. This is the first I ever heard of it. I would be willing to participate.

The likelihood of my needing a lung transplant or lobotomy is slim to none at this point

I don't anticipate any surgeries however I would be interested in donating lung tissue for research in the event of my death (which hopefully is a long time away!). It would be helpful to have the information available which could be made part of my Advanced Directives.

Would "situs" be of an issue when collecting samples ie.. LLL on an individual with situs inversus would be different than a normal situs? Currently I have planned to have a whole body donation with the Oregon Health Sciences University in Portland OR. Is there a better place for it to be sent?

This sounds like a wonderful program. There should be annual updates to the patient group.

Would you please be kind enough to send up information about this program. This is the first time that I have heard of it.