

WEBVTT

NOTE duration:"00:05:03"

NOTE recognizability:0.887

NOTE language:en-us

NOTE Confidence: 0.914720048461538

00:00:00.000 --> 00:00:02.196 I never saw a physician breakdown

NOTE Confidence: 0.914720048461538

00:00:02.196 --> 00:00:04.888 in tears until my son Howard died.

NOTE Confidence: 0.936964136666667

00:00:05.040 --> 00:00:06.576 This effects a lot of patients.

NOTE Confidence: 0.936964136666667

00:00:06.580 --> 00:00:08.540 It really effects their life,

NOTE Confidence: 0.936964136666667

00:00:08.540 --> 00:00:09.040 their livelihood,

NOTE Confidence: 0.936964136666667

00:00:09.040 --> 00:00:10.540 their ability to do their work

NOTE Confidence: 0.936964136666667

00:00:10.540 --> 00:00:12.286 to do the things that they love.

NOTE Confidence: 0.858552091

00:00:12.420 --> 00:00:14.330 So there's a really unique

NOTE Confidence: 0.858552091

00:00:14.330 --> 00:00:16.240 role for the patient community,

NOTE Confidence: 0.858552091

00:00:16.240 --> 00:00:17.248 especially in the disease.

NOTE Confidence: 0.858552091

00:00:17.248 --> 00:00:18.004 It's less known.

NOTE Confidence: 0.7383994

00:00:27.500 --> 00:00:29.990 For patients diagnosed with pulmonary

NOTE Confidence: 0.7383994

00:00:29.990 --> 00:00:32.789 fibrosis, time is critical. That's

NOTE Confidence: 0.81683474

00:00:32.800 --> 00:00:34.480 why Yale partnered with
NOTE Confidence: 0.81683474

00:00:34.480 --> 00:00:35.740 Three Lakes Foundation.
NOTE Confidence: 0.81683474

00:00:35.740 --> 00:00:37.515 They understand the impact of
NOTE Confidence: 0.81683474

00:00:37.515 --> 00:00:39.290 the diagnosis and a working
NOTE Confidence: 0.81683474

00:00:39.358 --> 00:00:41.228 to inspire hope in patients
NOTE Confidence: 0.81683474

00:00:41.228 --> 00:00:43.098 suffering with the lung disease.
NOTE Confidence: 0.81683474

00:00:43.100 --> 00:00:45.632 They are doing this by collaborating
NOTE Confidence: 0.81683474

00:00:45.632 --> 00:00:47.888 and uniting with researchers and
NOTE Confidence: 0.81683474

00:00:47.888 --> 00:00:49.888 institutions to accelerate the
NOTE Confidence: 0.81683474

00:00:49.888 --> 00:00:52.388 development of promising new technologies.
NOTE Confidence: 0.81683474

00:00:52.390 --> 00:00:55.654 And treatments it is a cause and a
NOTE Confidence: 0.81683474

00:00:55.654 --> 00:00:58.725 message that is bigger than all of us.
NOTE Confidence: 0.81683474

00:00:58.730 --> 00:00:59.070 Comma
NOTE Confidence: 0.915836846

00:00:59.080 --> 00:01:00.562 fibrosis really deserves
NOTE Confidence: 0.915836846

00:01:00.562 --> 00:01:01.550 different recognition.
NOTE Confidence: 0.915836846

00:01:01.550 --> 00:01:03.220 Pulmonary fibrosis is a rare

NOTE Confidence: 0.915836846

00:01:03.220 --> 00:01:05.249 disease and so that's part of

NOTE Confidence: 0.915836846

00:01:05.249 --> 00:01:07.019 the issue with lack of funding.

NOTE Confidence: 0.908705824615385

00:01:07.080 --> 00:01:08.360 You can increase disease

NOTE Confidence: 0.908705824615385

00:01:08.360 --> 00:01:10.280 awareness so you can really make

NOTE Confidence: 0.908705824615385

00:01:10.343 --> 00:01:12.520 a tangible difference. Pulmonary

NOTE Confidence: 0.90245634

00:01:12.530 --> 00:01:15.362 fibrosis is a progressive fatal lung

NOTE Confidence: 0.90245634

00:01:15.362 --> 00:01:17.978 disease affecting some 5 million

NOTE Confidence: 0.90245634

00:01:17.978 --> 00:01:20.120 people worldwide, maybe more.

NOTE Confidence: 0.906235883333333

00:01:20.210 --> 00:01:21.454 The disease was insidious.

NOTE Confidence: 0.906235883333333

00:01:21.454 --> 00:01:23.009 We knew that my son.

NOTE Confidence: 0.906235883333333

00:01:23.010 --> 00:01:23.878 Who's going to die?

NOTE Confidence: 0.906235883333333

00:01:23.990 --> 00:01:25.260 Art Kirschenbaum

NOTE Confidence: 0.948065362222222

00:01:25.270 --> 00:01:28.060 lost his son and his wife to the disease.

NOTE Confidence: 0.958103046666667

00:01:28.290 --> 00:01:32.706 She died December 2012 and shortly

NOTE Confidence: 0.958103046666667

00:01:32.706 --> 00:01:35.730 after that we discovered that my son,

NOTE Confidence: 0.958103046666667

00:01:35.730 --> 00:01:37.890 he reported that he also
NOTE Confidence: 0.958103046666667

00:01:37.890 --> 00:01:39.186 had pulmonary fibrosis.
NOTE Confidence: 0.958103046666667

00:01:39.190 --> 00:01:41.290 He died almost exactly two years
NOTE Confidence: 0.958103046666667

00:01:41.290 --> 00:01:43.669 later in the same ward at Yale,
NOTE Confidence: 0.958103046666667

00:01:43.670 --> 00:01:45.710 New Haven, with the same physician,
NOTE Confidence: 0.958103046666667

00:01:45.710 --> 00:01:47.754 I can tell you that watching him
NOTE Confidence: 0.958103046666667

00:01:47.754 --> 00:01:50.331 die was a hell of a lot worse
NOTE Confidence: 0.958103046666667

00:01:50.331 --> 00:01:52.120 than watching my wife died. The
NOTE Confidence: 0.87340005

00:01:52.130 --> 00:01:53.930 heartbreak and loss is felt.
NOTE Confidence: 0.87340005

00:01:53.930 --> 00:01:55.950 By patient and physician alike,
NOTE Confidence: 0.87340005

00:01:55.950 --> 00:01:57.890 and is magnified by frustration
NOTE Confidence: 0.87340005

00:01:57.890 --> 00:02:00.290 over a lack of awareness and
NOTE Confidence: 0.87340005

00:02:00.290 --> 00:02:02.200 funding to fight the disease.
NOTE Confidence: 0.820223062

00:02:02.380 --> 00:02:05.018 This is disease that 50% of the patient
NOTE Confidence: 0.820223062

00:02:05.018 --> 00:02:06.670 will die within three to five years.
NOTE Confidence: 0.820223062

00:02:06.670 --> 00:02:09.120 The other thing the disease is concentrated

NOTE Confidence: 0.820223062

00:02:09.120 --> 00:02:11.408 so in certain age is around 6070.

NOTE Confidence: 0.820223062

00:02:11.410 --> 00:02:12.998 It's actually more common

NOTE Confidence: 0.820223062

00:02:12.998 --> 00:02:14.983 than many of the cancers.

NOTE Confidence: 0.820223062

00:02:14.990 --> 00:02:16.106 All of us are afraid of.

NOTE Confidence: 0.898554128181818

00:02:16.500 --> 00:02:19.202 Loss of a family member to pulmonary

NOTE Confidence: 0.898554128181818

00:02:19.202 --> 00:02:21.123 fibrosis and frustration over the

NOTE Confidence: 0.898554128181818

00:02:21.123 --> 00:02:22.863 diagnosis and lack of treatment

NOTE Confidence: 0.898554128181818

00:02:22.863 --> 00:02:24.859 options led to the motivated.

NOTE Confidence: 0.898554128181818

00:02:24.860 --> 00:02:26.830 Real efforts to make changes.

NOTE Confidence: 0.949999971052632

00:02:26.900 --> 00:02:28.570 It's incredibly important that we

NOTE Confidence: 0.949999971052632

00:02:28.570 --> 00:02:30.637 have foundations like the Three Lakes

NOTE Confidence: 0.949999971052632

00:02:30.637 --> 00:02:32.659 Foundation that can really help us

NOTE Confidence: 0.949999971052632

00:02:32.659 --> 00:02:33.966 bring recognition, bring funding,

NOTE Confidence: 0.949999971052632

00:02:33.966 --> 00:02:35.844 and really move the field forward.

NOTE Confidence: 0.916956421428571

00:02:35.920 --> 00:02:40.000 I think their focus on accelerating

NOTE Confidence: 0.916956421428571

00:02:40.000 --> 00:02:41.584 therapeutics, increasing awareness,
NOTE Confidence: 0.916956421428571

00:02:41.584 --> 00:02:43.844 making a measurable difference in
NOTE Confidence: 0.916956421428571

00:02:43.844 --> 00:02:46.773 the life of patients with pulmonary
NOTE Confidence: 0.916956421428571

00:02:46.773 --> 00:02:49.530 fibrosis is really exciting. Foundation
NOTE Confidence: 0.953633967777778

00:02:49.540 --> 00:02:51.808 funding, technology and collaboration
NOTE Confidence: 0.953633967777778

00:02:51.808 --> 00:02:54.643 resulted in dramatic innovation to
NOTE Confidence: 0.755734251666667

00:02:54.660 --> 00:02:56.910 start doing the pulmonary fibrosis Atlas.
NOTE Confidence: 0.755734251666667

00:02:56.910 --> 00:02:59.409 We wanted to do this technology of
NOTE Confidence: 0.755734251666667

00:02:59.409 --> 00:03:01.868 being able to profile every single
NOTE Confidence: 0.755734251666667

00:03:01.868 --> 00:03:04.496 cell in the pulmonary fibrosis lung
NOTE Confidence: 0.755734251666667

00:03:04.496 --> 00:03:07.466 to understand how abnormal they are.
NOTE Confidence: 0.755734251666667

00:03:07.470 --> 00:03:09.560 To try to start thinking how we can fix them
NOTE Confidence: 0.872861154615385

00:03:09.810 --> 00:03:11.786 through high resolution mapping,
NOTE Confidence: 0.872861154615385

00:03:11.786 --> 00:03:13.762 they've created a cellular
NOTE Confidence: 0.872861154615385

00:03:13.762 --> 00:03:16.240 blueprint of the human lung. We've
NOTE Confidence: 0.889345131818182

00:03:16.250 --> 00:03:18.056 never studied them at this detail

NOTE Confidence: 0.889345131818182
00:03:18.056 --> 00:03:19.480 and that's a completely new
NOTE Confidence: 0.875339479
00:03:19.490 --> 00:03:21.735 area of research and discoveries
NOTE Confidence: 0.875339479
00:03:21.735 --> 00:03:23.980 of completely new cell types,
NOTE Confidence: 0.75330976
00:03:24.050 --> 00:03:27.025 but I committed to three lakes it.
NOTE Confidence: 0.75330976
00:03:27.030 --> 00:03:28.500 We'll put the data public
NOTE Confidence: 0.75330976
00:03:28.500 --> 00:03:29.676 before we publish it.
NOTE Confidence: 0.870500345
00:03:29.950 --> 00:03:32.596 The pulmonary fibrosis cell Atlas is
NOTE Confidence: 0.870500345
00:03:32.596 --> 00:03:36.330 now an easy to use web tool for anyone
NOTE Confidence: 0.870500345
00:03:36.330 --> 00:03:38.800 and everyone, and we did it. It's
NOTE Confidence: 0.964705702
00:03:38.810 --> 00:03:40.290 hard to assess the impact.
NOTE Confidence: 0.964705702
00:03:40.290 --> 00:03:42.817 I know there's been around 20 new
NOTE Confidence: 0.964705702
00:03:42.817 --> 00:03:44.876 discoveries just in our field
NOTE Confidence: 0.964705702
00:03:44.876 --> 00:03:46.676 and pulmonary fibrosis fund
NOTE Confidence: 0.964705702
00:03:46.676 --> 00:03:48.476 this publicly available data
NOTE Confidence: 0.903666724545454
00:03:48.710 --> 00:03:50.760 innovation is leading to drug
NOTE Confidence: 0.903666724545454

00:03:50.760 --> 00:03:53.280 discovery and the repurposing of drugs.
NOTE Confidence: 0.923446942857143

00:03:53.590 --> 00:03:55.038 This is incredibly important
NOTE Confidence: 0.923446942857143

00:03:55.038 --> 00:03:56.848 because the two medications that
NOTE Confidence: 0.923446942857143

00:03:56.848 --> 00:03:58.607 are available on the market.
NOTE Confidence: 0.923446942857143

00:03:58.610 --> 00:03:59.994 Can slow progression and
NOTE Confidence: 0.923446942857143

00:03:59.994 --> 00:04:01.724 do have some side effects?
NOTE Confidence: 0.923446942857143

00:04:01.730 --> 00:04:03.590 They're not perfect medications, though.
NOTE Confidence: 0.923446942857143

00:04:03.590 --> 00:04:05.190 They're better than what we used to have.
NOTE Confidence: 0.923446942857143

00:04:05.190 --> 00:04:07.591 We need new medications that are better
NOTE Confidence: 0.923446942857143

00:04:07.591 --> 00:04:10.273 that can halt the progression of fibrosis
NOTE Confidence: 0.923446942857143

00:04:10.273 --> 00:04:12.643 that can have fewer side effects.
NOTE Confidence: 0.923446942857143

00:04:12.650 --> 00:04:14.394 And this is what we're working on here,
NOTE Confidence: 0.872151796842105

00:04:14.450 --> 00:04:17.002 and the idea is that drugs that reverse
NOTE Confidence: 0.872151796842105

00:04:17.002 --> 00:04:19.103 fibrosis in this computational method
NOTE Confidence: 0.872151796842105

00:04:19.103 --> 00:04:21.899 could be prioritized for clinical trials.
NOTE Confidence: 0.944652104444445

00:04:22.040 --> 00:04:23.732 More patient participation in

NOTE Confidence: 0.944652104444445

00:04:23.732 --> 00:04:25.847 clinical trials is a necessity,

NOTE Confidence: 0.944652104444445

00:04:25.850 --> 00:04:28.874 as researchers work to slow the disease.

NOTE Confidence: 0.944652104444445

00:04:28.880 --> 00:04:31.082 And provide hope for those who

NOTE Confidence: 0.944652104444445

00:04:31.082 --> 00:04:32.550 have already suffered enough.

NOTE Confidence: 0.86978297875

00:04:32.740 --> 00:04:34.612 You're not supposed to see your

NOTE Confidence: 0.86978297875

00:04:34.612 --> 00:04:37.028 children die, and that was terrible,

NOTE Confidence: 0.923077354117647

00:04:37.040 --> 00:04:37.740 terrible, terrible.

NOTE Confidence: 0.923077354117647

00:04:37.740 --> 00:04:39.490 The Three Lakes Foundation is

NOTE Confidence: 0.923077354117647

00:04:39.490 --> 00:04:41.302 really helping us accelerate time

NOTE Confidence: 0.923077354117647

00:04:41.302 --> 00:04:43.057 from discovery to patient care,

NOTE Confidence: 0.923077354117647

00:04:43.060 --> 00:04:44.370 and that's what is vital.

NOTE Confidence: 0.888627967391304

00:04:44.410 --> 00:04:46.090 That's really important, because in

NOTE Confidence: 0.888627967391304

00:04:46.090 --> 00:04:48.419 the future we would like to diagnose

NOTE Confidence: 0.888627967391304

00:04:48.419 --> 00:04:50.491 the disease early so that we could

NOTE Confidence: 0.888627967391304

00:04:50.491 --> 00:04:52.390 design interventions that cure it.