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Survey Queue

Autoimmune Hepatitis and Liver Transplant Patient Survey

Please complete the survey below to the best of your ability.

Thank you so much for your time and participation!

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Demographics

1 ID Number:

* must provide value

This will be given to you

2 Age:

* must provide value

in years

3 Sex:

* must provide value

- ☐ Male
☐ Female
☐ Prefer not to say
☐ Other

reset

4 Race/Ethnicity:

* must provide value

- ☐ White
☐ Black/African American
☐ Hispanic/Latino
☐ Native American/American Indian
☐ Asian/Pacific Islander
☐ Other

Check all that apply

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Autoimmune Hepatitis and Liver Transplant Patient Survey

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Medical Information

5 Are you an autoimmune hepatitis or liver transplant patient?

* must provide value

- ☐ Autoimmune Hepatitis (AIH)
☒ Liver Transplant (LT)

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Note: if you received a liver transplant at any point in your life, you are a liver transplant patient

6 What medication are you currently taking for your Liver Transplant (LT)?

* must provide value

- ☐ Azathioprine (Azasan)
☐ Prednisone (Deltasone, Rayos, Prednisone Intenol)
☐ Tacrolimus (Prograf, Protopic, Astagraf XL, Envarsus XR)
☐ Sirolimus (Rapamune)
☐ Everolimus (Zortress, Afinitor, Afinitor Disperz)
☐ Mycophenolate (Myfortic, CellCept)
☐ Cyclosporine (Neoral, Sandimmune, Gengraf)
☐ Other

7 Please indicate if you have or have had any of the following conditions:

* must provide value

- ☐ Esophageal varices
☐ Jaundice
☐ Ascites
☐ Hepatic Encephalopathy
☐ Portal Hypertension
☐ Liver Cirrhosis
☐ I have never had any of these conditions

8 Please indicate if you have experienced any of the following complications of your immunosuppression medication:

* must provide value

- ☐ Infection
☐ Cancer
☐ Kidney problems
☐ Side effects (weight gain, high blood pressure, vomiting, skin rash, etc.)
☐ None of these
☐ Other

9 Please write down any other medical conditions you currently have:

* must provide value

[Expand](#)

If none, write "N/A"

What was the date of your liver transplant?

* must provide value



Today

M-D-Y

MM-DD-YYYY

**What was the reason for your liver transplant
(disease or condition name listed for UNOS)?**

**10 Please indicate the number of liver transplant
rejections in your lifetime:**

* must provide value

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 or more

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Autoimmune Hepatitis and Liver Transplant Patient Survey

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Medical Information

5 Are you an autoimmune hepatitis or liver transplant patient?

* must provide value

☒ Autoimmune Hepatitis (AIH)

☐ Liver Transplant (LT)

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Note: if you received a liver transplant at any point in your life, you are a liver transplant patient

6 What medication are you currently taking for your Autoimmune Hepatitis (AIH)?

* must provide value

☐ Azathioprine (Azasan)

☐ Prednisone (Deltasone, Rayos, Prednisone Intensol)

☐

Tacrolimus (Prograf, Protopic, Astagraf XL, Envarsus XR)

☐ Sirolimus (Rapamune)

☐ Everolimus (Zortress, Afinitor, Afinitor Disperz)

☐ Mycophenolate (Myfortic, CellCept)

☐ Cyclosporine (Neoral, Sandimmune, Gengraf)

☐ Other

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☐ Esophageal varices

☐ Jaundice

☐ Ascites

☐ Hepatic Encephalopathy

☐ Portal Hypertension

☐ Liver Cirrhosis

☐ I have never had any of these conditions

8 Please indicate if you have experienced any of the following complications of your immunosuppression medication:

* must provide value

☐ Infection

☐ Cancer

☐ Kidney problems

☐ Side effects (weight gain, high blood pressure, vomiting, skin rash, etc.)

☐ None of these

☐ Other

9 Please write down any other medical conditions you currently have:

* must provide value

[Expand](#)

If none, write "N/A"

10 Please indicate the number of autoimmune hepatitis flare-ups in your lifetime:

*** must provide value**

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 or more

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AutoImmune Hepatitis and Liver Transplant Patient Survey

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Survey

Please indicate your level of agreement with the following statements:

11 I take my immunosuppression medication(s) without difficulty or concern.

* must provide value

- ☐ 1 (Strongly disagree)
☐ 2 (Disagree)
☐ 3 (Neutral)
☐ 4 (Agree)
☐ 5 (Strongly agree)

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12 I know what side effects to expect from my immunosuppressive medication(s).

* must provide value

- ☐ 1 (Strongly disagree)
☐ 2 (Disagree)
☐ 3 (Neutral)
☐ 4 (Agree)
☐ 5 (Strongly agree)

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13 I experience unpleasant side effects from my immunosuppressive medication(s).

* must provide value

- ☐ 1 (Strongly disagree)
☐ 2 (Disagree)
☐ 3 (Neutral)
☐ 4 (Agree)
☐ 5 (Strongly agree)

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14 I feel financially burdened by the immunosuppressive medication(s) I need to take.

* must provide value

- ☐ 1 (Strongly disagree)
☐ 2 (Disagree)
☐ 3 (Neutral)
☐ 4 (Agree)
☐ 5 (Strongly agree)

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15 My physician and I have discussed the possibility of withdrawing my immunosuppressive medication(s).

* must provide value

- ☐ 1 (Strongly disagree)
☐ 2 (Disagree)
☐ 3 (Neutral)
☐ 4 (Agree)
☐ 5 (Strongly agree)

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16 I want to attempt withdrawal of immunosuppressive therapy.

*** must provide value**

- ☒ 1 (Strongly disagree)
☐ 2 (Disagree)
☐ 3 (Neutral)
☐ 4 (Agree)
☐ 5 (Strongly agree)

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17 Please rank the most important reason you do not want to attempt immunosuppression withdrawal:

*** must provide value**

- ☐ I do not want to risk a flareup
☐ I do not want to risk needing a liver transplant
☐ I do not want to take more medications if I fail withdrawal
☐ I do not want to "rock the boat"
☐ I am doing well on my immunosuppressants
☐ Other

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18 Please rank the 2nd most important reason you do not want to attempt immunosuppression withdrawal:

*** must provide value**

- ☐ I do not want to risk a flareup
☐ I do not want to risk needing a liver transplant
☐ I do not want to take more medications if I fail withdrawal
☐ I do not want to "rock the boat"
☐ I am doing well on my immunosuppressants
☐ Other

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16 I want to attempt withdrawal of immunosuppressive therapy.

* must provide value

- ☐ 1 (Strongly disagree)
- ☐ 2 (Disagree)
- ☐ 3 (Neutral)
- ☒ 4 (Agree)
- ☐ 5 (Strongly agree)

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18 Please rank the 2nd most important reason you want to attempt immunosuppression withdrawal:

* must provide value

- ☐ I want to stop experiencing side effects from my immunosuppressants
- ☐ I want to avoid the risk of major complications from my immunosuppressants (cancer, kidney problems, infection, etc.)
- ☐ I want to decrease the money I spend on immunosuppressants
- ☐ I want to avoid taking pills for the rest of my life
- ☐ Other

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17 Please rank the most important reason you want to attempt immunosuppression withdrawal:

* must provide value

- ☐ I want to stop experiencing side effects from my immunosuppressants
- ☐ I want to avoid the risk of major complications from my immunosuppressants (cancer, kidney problems, infection, etc.)
- ☐ I want to decrease the money I spend on immunosuppressants
- ☐ I want to avoid taking pills for the rest of my life
- ☐ Other

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