You are living with the hepatitis B virus.

Please respond to this inaugural national survey that marks the launch of the first *Etats Généraux de l’Hépatite B* (hepatitis B national consultations).

Enhancing the visibility of the real consequences of hepatitis B and optimising the care and follow-up of patients suffering from chronic hepatitis B are the two main stakes behind the launch of the national consultations through the SOS Hépatites association and many partners (associations of people living with hepatitis B, health professionals and health institutions).

Today, the hepatitis B collective is enlisting your help to complete an initial survey designed to make an inventory of the main impacts of this illness, as well as your main needs and expectations in terms of improving your daily life.

The questionnaire enquires about:

-- your perception of hepatitis B
-- screening of your loved ones
-- your medical and therapeutic care
-- your everyday difficulties and expectations

You will need 15 minutes to complete this questionnaire.

Your responses are collected and processed under strictly anonymous and confidential conditions. The findings will be all the more impactful if many of you respond! They should help raise awareness among health authorities and the public in order to obtain “fair” recognition of the real difficulties we face when suffering from hepatitis B.

If you would like to be informed of the results of this survey, do not hesitate to send us your request:
- by email to vero.ecoutemoi@soshepatites.org
  or
Thank you for participating!

*SOS Hépatites, AIDES, ASUD (Self-Support for Drug Users), CHV (Viral Hepatitis Collective) – TRT5 (therapeutic treatment & research inter-association group), Transhépate, AFEF (French association for the study of the liver), ANGH (National Association of Hepatic-Gastroenterologists of General Hospitals), APSEP (Association for Health Professionals Serving in Prison), COMEDE (Health committee for individuals in exile), CREGG (Brainstorming club for hepatic-gastroenterology clinics and groups), FPRH (Federation of reference divisions and networks, and hepatitis networks), Médecins du monde, Family Planning, Agence nationale de la biomédecine (National biomedicine agency), ANRS (National Agency for Research on Aids and Viral Hepatitis), Cochin Hospital, Pitié Salpêtrière-Paris Hospital, Lille university hospital, Renne university hospital, Strasbourg university hospital, CIC (immunisation clinical investigation centre) of the Cochin-Paris Hospital, Croix Rousse-Lyon Hospital, Saint Joseph-Marseille Hospital, INSERM (National Institute of Health and Medical Research), BMSH V (Bordeaux Metropolis without Hepatitis).

* 1. In which year was your hepatitis B detected?
**Your perception of hepatitis B**

* 2. Do you think hepatitis B is an illness?
   - [ ] yes
   - [ ] no
   - [ ] I don’t know

* 3. Do you think hepatitis B is an illness that is
   - [ ] mildly serious
   - [ ] serious
   - [ ] very serious
   - [ ] is not really an illness
   - [ ] I don’t know

* 4. Please indicate whether you think hepatitis B is more or less serious than the listed illnesses

<table>
<thead>
<tr>
<th>Illness</th>
<th>less serious</th>
<th>as serious</th>
<th>more serious</th>
<th>I don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>heart attack</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>excess cholesterol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>lung cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
* 5. Had you heard of hepatitis B before being tested?
   - yes
   - no
   - I don’t know

* 6. Did you feel concerned by hepatitis B before being tested?
   - yes
   - no
   - I don’t know
**Your perception of hepatitis B (2)**

* 7. Please indicate whether you agree or disagree with the following statements

<table>
<thead>
<tr>
<th>Statement</th>
<th>strongly agree</th>
<th>somewhat agree</th>
<th>somewhat disagree</th>
<th>strongly disagree</th>
<th>no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B is linked to a virus that is present in blood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B can lead to chronic liver disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B cannot be cured today (in 2019)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B is transmitted through blood exchange between two people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B is transmitted during unprotected sexual intercourse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B can lead to liver cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B affects more people than HIV/AIDS in the world</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B can lead to significant fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>Somewhat Agree</td>
<td>Somewhat Disagree</td>
<td>Strongly Disagree</td>
<td>No Opinion</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>---------------</td>
<td>-------------------</td>
<td>------------------</td>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>Hepatitis B can lead to joint problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B is the focus of much medical research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is advisable to stop drinking alcohol when you have hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is advisable to stop smoking when you have hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B can manifest as muscle pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B is transmitted through saliva exchange between two people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a vaccine against hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B can be transmitted from mother to child during childbirth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* 8. Today, do you feel you are well aware of

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Somewhat No</th>
<th>Not at All</th>
<th>No Opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to avoid passing hepatitis B on to your loved ones in everyday life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to talk to your loved ones about hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to talk about hepatitis B with a new sexual partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How hepatitis B treatment works</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to monitor your hepatitis B?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9. On what occasion(s) did you obtain this information?

- during screening
- during medical consultations
- by searching for yourself
- when interacting with others affected by the virus
- Other (please specify)

10. Today, among the impacts of hepatitis B, which one is the most challenging for you (several answers possible)

- fear of rejection
- uncertainty about disease progression
- lack of support from others
- disrupted sex life
- discouragement
- professional activities
- recreational opportunities
- the treatments
- fear of cancer
- fear of dying
- fear of infecting others
- how to have children with hepatitis B
* 11. Who offered or prescribed hepatitis B testing for you?
- your general practitioner
- another doctor
- a free anonymous screening centre [CEGIDD: Free Infection Screening and Diagnosis Information Centre: by the Human Immunodeficiency Virus (HIV), viral hepatitis and Sexually Transmitted Infections (STIs)]
- during a pregnancy or pregnancy plan
- I don’t know
someone else (please specify)

* 12. Did you have your liver examined (lab tests, ultrasound, or liver biopsy) after your hepatitis B screening?
- yes
- no
- I don’t know

If yes, please specify which one.
13. After the screening, did you manage to talk to loved ones about your hepatitis B quickly?

<table>
<thead>
<tr>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than one month</td>
<td></td>
</tr>
<tr>
<td>less than one year</td>
<td></td>
</tr>
<tr>
<td>more than one year</td>
<td></td>
</tr>
</tbody>
</table>

If yes, please specify which loved on(s) (sexual partner, rest of the family, friends, etc.)

14. If so, why? (several answers possible)

- [ ] to be honest with them
- [ ] to encourage them to be screened to
- [ ] encourage them to get vaccinated
- [ ] for their support
- [ ] other (please specify)

15. If not, why not (several answers possible)

- [ ] fear of being rejected because I am sick
- [ ] fear of being rejected because I can transmit the illness
- [ ] Other (please specify)

16. Do you trust the hepatitis B vaccine?

- [ ] yes
- [ ] no
- [ ] I don’t know

17. Have you discussed hepatitis B prevention with loved ones? (Screening-Vaccination)?

- [ ] yes
- [ ] no
18. Are you taking any hepatitis B medication?
   - yes
   - no (if this choice, go directly to question 25)

19. If yes, is it a treatment that is
   - oral
   - injected under the skin (Interferon)
   - not concerned
   - other (please specify)

20. What hepatitis B medication is it?

   - Tenofovir (Viread or generic)
   - Entecavir (Baraclude or generic)
   - not concerned
   - Other (please specify)
21. Do you ever forget to take your hepatitis B medication?

- never
- sometimes
- often
- not concerned

22. If you happen to forget or not take your medication, what are the reasons? (many options possible)

- weariness
- lack of motivation
- to feel better (fewer side effects)
- simply forgetting
- delay in refilling treatment at the pharmacy
- an unexpected event that resulted in you not having any medication with you
- not concerned
- other (please specify)

23. Do you know why you need to take treatment?

- yes
- no
- not concerned

24. Do you have any side effects?

- yes
- no
- not concerned

If yes, which one(s) (please specify)
25. If you are not taking any treatment, please tick the situations that apply to you (several answers possible)

☐ I've never heard of it before

☐ Your doctor tells you that you don't need any

☐ You refuse to take the treatment

☐ You would have liked treatment

☐ not concerned

☐ Other (please specify)
Your medical follow-up

* 26. Have you been prescribed an ultrasound to monitor your liver?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Yes</th>
<th>No</th>
<th>I don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>every 6 months</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>once a year</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>other frequency</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

* 27. Do you know if you have fibrosis?

- yes
- no
- I don't know
- other (please specify)
28. Which doctor(s) or professional(s) have you consulted (or sought out) in the past 12 months regarding your hepatitis B (several answers possible)

- general practitioner
- hepatologist
- gynaecologist
- physiotherapist
- nurse
- chemist
- therapeutic educator
- surgeon
- psychiatrist
- volunteer or association manager
- social worker
- psychologist
- sports and/or physical activity professional
- none
- Other (please specify)

[ ]
**29. The consequences and impacts of your hepatitis B on your daily life (today)**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes, significantly</th>
<th>Yes, moderately</th>
<th>Not really</th>
<th>Not at all</th>
<th>No opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your hepatitis B affect your morale?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your family life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your social activities (cultural outings, with friends, etc.)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your leisure time?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your work life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your sex life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your relationship as a couple?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B affect your self-image?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your hepatitis B interfere with your physical activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**30. Were you offered or prescribed Hepatitis Delta (hepatitis D) testing?**

- [ ] Yes
- [ ] No
- [ ] I don’t know

**31. You are living with the hepatitis Delta virus (Hepatitis D)**

- [ ] Yes
- [ ] No
- [ ] I don’t know
* 32. Are you concerned by one or more of these health issues:

- [ ] HIV/AIDS
- [ ] other chronic diseases: diabetes, asthma, allergies, etc.
- [ ] kidney failure
- [ ] awaiting liver transplant
- [ ] I have no health problems other than hepatitis B
- [ ] Other (please specify)
* 33. On a daily basis, who is/are the person(s) who helps/help and supports/support you against hepatitis B

- your spouse
- your children
- your parents
- your friends
- your doctor
- a patients’ association
- no one

Other (please specify)

* 34. For you, does hepatitis B generate specific financial expenses

- yes
- no

If yes, please specify the nature of the expense(s) and the amount?


* 35. What are your needs in terms of better managing your hepatitis B and improving your daily life?

<table>
<thead>
<tr>
<th>Need</th>
<th>Yes</th>
<th>No</th>
<th>No Opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better informed about healthcare professionals who can help you with your care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about the treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about preventing transmission to loved ones</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about the disease in general</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about medical follow-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about potential difficulties in working life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about difficulties when applying for a mortgage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better informed about what you can eat and drink</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meet and discuss with other sick people</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
* 36. What do you expect from a patient association such as SOS Hépatites or the *États Généraux de l'hépatite B* (Hepatitis B national consultations)?

<table>
<thead>
<tr>
<th>Expectation</th>
<th>Yes, significantly</th>
<th>Yes, moderately</th>
<th>Not really</th>
<th>Not at all</th>
<th>No opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>to be able to contact someone easily to ask my questions (e.g. toll-free number)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to have access to information on hepatitis B and daily life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to have access to social information in order to better manage the consequences of hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>raise awareness of the challenges of people living with hepatitis B among health policy and decision makers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to promote vaccination in adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to extend the vaccination obligation until adolescence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to allow people living with hepatitis B to opt for the career of their choice, including those that they are currently barred from</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>develop a website dedicated to hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>set up a toll-free number dedicated to hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>draft hepatitis B information brochures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other (please specify)
LivingWithHepatitisBSurvey

Your profile

* 37. Your gender
   - female
   - male
   - other (please specify)

* 38. Your age group
   - Age 16-30
   - Age 30-60
   - Over 60-years-old

* 39. Your department (please specify)

* 40. You live
   - in a rural area
   - in an urban area

* 41. You live
   - alone
   - as a couple or family
42. You have children
- yes
- no

Any comments

43. Do you have loved ones (family, friends, etc.) who are also affected by hepatitis B?
- yes
- no
- I don't know

Any comments

44. What is your education level?
- lower secondary studies
- high school
- professional certificate
- higher education
- no diploma
- I do not wish to answer

45. Professional status
- active
- no occupation
- in search of work
- retired

46. Were you born in France?
- yes
- no

If not, what is your country of origin?
47. If not, how long have you been in France?

- [ ] less than 3 months
- [ ] less than 1 year
- [ ] between 1-5 years
- [ ] more than 5 years
LivingWithHepatitisBSurvey

Thank you for participating

48. Did you complete the survey
   ○ alone
   ○ with someone’s help

   if with someone’s help specify the name of his/her organisation

49. Please provide us with your feedback and suggestions on improving the questionnaire