Registre français de l'échinococcose alvéolaire (FrancEchino)
QUESTIONNAIRE MEDICAL

Adresse du réseau :
Centre National de Référence Echinococcoses
Service de Parasitologie-Mycologie
CHU de Besançon, Hôpital Jean-Minjoz
3 boulevard Fleming, 25030 Besançon cedex
E-mail : cnr-echino@chu-besancon.fr

Responsables du réseau :
Pr L. Millon (Parasitologie CHU Besançon)
Dr AP. Bellanger-Clerget (Parasitologie CHU Besançon)
Pr S. Bresson-Hadni (Parasitologie CHU Besançon)
Dr C. Richou (Hépatologie CHU Besançon)
Dr D. Weil-Verhoeven (Hépatologie CHU Besançon)

#1 – ADMINISTRATIVE DATA

#1.1 – Administrative information

PATIENT :

Last name : _ Birth name : _

First name : _

Birthdate : |__|__|/|__|__|/|__|__|__|__| Gender : O Male O Female

Adress : _

Name of the person who filled the form : _ Date : _ _ _ _ _ _ _ _ _ _

Reserved to the CNR Echinococcoses :

Name of the center : _ (FrancEchino n° : |__|__|__|)

EurEchino Database Subject ID (ref patient) : |__|__|__| – |__|__|__| – |__|__|__| – |__|__|

Inclusion date : |__|__|/|__|__|/|__|__|__|__| Year of diagnosis : |__|__|__|__|

#1.2 – General follow-up

Date of diagnosis* |__|__|/|__|__|/|__|__|__|__|

*Date of the exam which made the diagnosis "probable" or "confirmed"

Age at diagnosis : |__|__|__|__|__|

Patient's vital status : O Alive O Death

Date of death : |__|__|/|__|__|/|__|__|__|__| Death related to AE ? O Yes O No O Uk

Tel. 03.70.63.23.50 – Fax. 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#1.3 – Doctors

#1.3.1 – INVESTIGATOR / REFFERING PHYSICIAN (in charge of the diagnosis and/or follow-up) :

Hospital : _ Department : _

City : _ Zip code : _ _ _ _ _ _ _ _ _

Doctor last name : _

Doctor first name : _

Tel (direct) : _

Tel (secretary) : _

Email : _

Medical speciality :

- ○ General medicine
- ○ Hepato-gastroenterologist (HGE)
- ○ Surgeon
- ○ Infectiologist
- ○ Biologist
- ○ Radiologist
- ○ Hospital doctor
- ○ CNR Doctor
- ○ Other speciality

#1.3.2 – Other doctors :

First name	Last name	Medical speciality	Adress	Post code	City
…	…		…	…	…
…	…		…	…	…

#2 – EPIDEMIOLOGICAL DATA

Refer to the form « Questionnaire epidemiologique (patient) »

Tel. 03.70.63.23.50 – Fax. 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#3 – MEDICAL DATA

#3.1 – Diagnosis

Complet the "Date of diagnosis" in (#1.2)

Circumstances of diagnosis :

- ○ Signs and symptoms
- ○ Incidental finding
- ○ Screening
- ○ Family case

Required information :

Jaundice : O Yes O No

Cholangitis : O Yes O No

Liver abscess : O Yes O No

Portal hypertension : O Yes O No

Optional information :

Alteration of general status : O Yes O No

Pain : O Yes O No

Pruritus : O Yes O No

Hepatomegaly : O Yes O No

Ascites : O Yes O No

Splenomegaly : O Yes O No

Stomach hemorrhage : O Yes O No

Oesophageal varices : O Yes O No

Budd-Chiari syndrome : O Yes O No

Other : O Yes O No

If "Other", please explain :

_ _
_ _
_ _ _ _ _ _ _ _ _ _

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#3.2 – Liver lesions

Liver lesions : O Yes O No

If "yes" :

Single/Multiple Lesion(s) : O Unique O Multiple

Lobe affected :

- ○ Right lobe
- ○ Left lobe
- ○ Both

Central biliary or vascular infiltration of one lobe : O Yes O No

Central biliary or vascular infiltration of both lobe : O Yes O No

Any liver lesion with extension along the vessels and the biliary tree : O Yes O No

Calcification detected : O Yes O No

Number of lesions : |__|__|__|__|__|

Segments involved : □ S1 □ S2 □ S3 □ S4 □ S5 □ S6 □ S7 □ S8

Size of the largest lesion : |__|__|__|__|__| mm

Range :

- ○ < 20 mm
- ○ 20-50 mm
- ○ 50-100 mm
- ○ > 100 mm

Liver hilum involvement : O Yes O No

Intrahepatic bile duct dilatation : O Yes O No

Inferior vena cava injury : O Yes O No

Portal vein injury : O Yes O No

Suprahepatic veins injury : O Yes O No

Necrosis detected : O Yes O No

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

If "no" :

Primary extrahepatic without liver involment : O Yes O No

If "yes", please specify :

Organ :

- ☐ lung
- ☐ liver
- ☐ central nervous system
- ☐ bone
- ☐ spleen
- ☐ diaphragm
- ☐ pancreas
- ☐ kidney
- ☐ adrenals
- ☐ pleura
- ☐ pulmonary system
- ☐ muscle
- ☐ organ lining
- ☐ member
- ☐ heart
- ☐ Abdominal wall, parietal muscles
- ☐ other localisation

#3.3 – Invasion of neighbour organs

Invasion of neighbor organs/tissues ? O Yes O No O Not checked

Organ	Discovered at diagnosis	Discovery year	Secondary lesions size
		|__|__|__|__|	|__|__|__|__| , |__|__|__| mm
		|__|__|__|__|	|__|__|__|__| , |__|__|__| mm
		|__|__|__|__|	|__|__|__|__| , |__|__|__| mm

#3.4 – Metastasis, metastases

Metastasis/metastases ? O Yes O No O Not completely evaluated

Organ	Discovered at diagnosis	Discovery year	Secondary lesions size
		|__|__|__|__|	|__|__|__|__| , |__|__|__| mm
		|__|__|__|__|	|__|__|__|__| , |__|__|__| mm
		|__|__|__|__|	|__|__|__|__| , |__|__|__| mm

#3.5 – Staging

P : |__|__|
N : |__|__|
M : |__|__|

O Stade I
O Stade II
O Stade IIIa
O Stade IIIb
O Stade IV

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

PNM classification of alveolar echinococcosis

P	**Hepatic localisation of the Parasite**
P X	Primary tumor cannot be assessed
P 0	No detectable tumor in the liver
P 1	Peripheral lesions without proximal vascular and/or biliar involvement
P 2	Central lesions with proximal vascular and/or biliar involvement of one lobe[a]
P 3	Central lesions with hilar vascular or biliar involvement of both lobes and/ or with involvement of two hepatic veins
P 4	Any liver lesion with extension along the vessels[b] and the biliary tree
N	**Extra hepatic involvement of neighbouring organs** [diaphragm, lung, pleura, pericardium, heart, gastric and duodenal wall, adrenal glands, peritoneum, retroperitoneum, parietal wall (muscles, skin, bone), pancreas, regional lymph nodes, liver ligaments, kidney]
N X	Not evaluable
N 0	No regional involvement
N 1	Regional involvement of contiguous organs or tissues
M	**The absence or presence of distant Metastasis** [lung, distant lymph nodes, spleen, CNS, orbital, bone, skin, muscle, kidney, distant peritoneum and retroperitoneum]
M X	Not completely evaluated
M 0	No metastasis[c]
M 1	Metastasis

PNM stage grouping of alveolar echinococcosis

Stage I	P1	N0	M0
Stage I	P2	N0	M0
Stage IIIa	P3	N0	M0
Stage IIIb	P1– 3	N1	M0
	P4	N0	M0
Stage IV	P4	N1	M0
	Any P	Any N	M1

Selon :

Pawłowski Z.S., Eckert J., Vuitton D.A., Ammann R.W., Kern P., Craig P.S., Dar K.F., De Rosa F., Filice C., Gottstein B., Grimm F., Macpherson C.N.L., Sato N., Todorov T., Uchino J., von Sinner W. andWen H., 2001, Echinococcosis in humans: clinical aspects, diagnosis and treatment. In : WHO/OIE Manual on Echinococcosis in humans and animals: a public health problem of global concern, Eckert J., Gemmell M.A., Meslin F.X. et Pawlowski Z.S. (eds.), OIE/WHO, Paris, 20-72.

Kern P., Wen H., Sato N., Vuitton D.A., Gruener B., Shao Y., Delabrousse E., Kratzer W., Bresson-Hadni S., 2006, WHO classification of alveolar echinococcosis: principles and application. Parasitol Int 55 Suppl, S283-287.)

[a] For classification, the plane projecting between the bed of the gall bladder and the inferior vena cava divides the liver in two lobes.
[b] Vessels mean inferior vena cava, portal vein and arteries.
[c] Chest X-ray and cerebral CT negative.

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#3.6 – Immunodeficiency before diagnosis

Immunosuppression-associated condition before AE diagnosis? O Yes O No

if "yes" :

- ☐ Any solid cancer
- ☐ Hematological malignancy
- ☐ Organ or tissue transplantation
- ☐ Chronic inflammatory disorder
- ☐ AIDS

Immunosuppressive treatment ? O Yes O No

if "yes" :

- ☐ Corticodteroids
- ☐ Cancer chemotherapy
- ☐ Chemical immunosuppressants
- ☐ Biological therapeutic agents

#4 – MEDICAL IMAGING

#4.1 – Imaging techniques used for diagnosis

Imaging technique *	Organ	Lesion detected (Y/N)	Exam date
			__/__/____
			__/__/____
			__/__/____
			__/__/____
			__/__/____
			__/__/____

#4.2 – Imaging follow-up

Imaging technique *	Organ	New lesion / Evolution**	Exam date
			__/__/____
			__/__/____

*Ultra Sound (US) or Computed Tomography (CT) or Magnetic Resonance Imaging (MRI) or Positive Electron Tomography (PET)

**New lesion detected or Evolution of a lesion (progression / regression / stable)

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#5 – MEDICAL TREATMENT

#5.1 – Antiparasitic drug

Anti-parasitic Drug ? O Yes O No

Name of the drug*	Date of initiation	Dose	Unit	Fre-quency	Date of withdrawal	Side-effect** (Y/N)	Drug monitoring (Y/N)
	|__|__|/|__|__|/|__|__|__|__|	|__|__|__|__|			|__|__|/|__|__|/|__|__|__|__|		
	|__|__|/|__|__|/|__|__|__|__|	|__|__|__|__|			|__|__|/|__|__|/|__|__|__|__|		
	|__|__|/|__|__|/|__|__|__|__|	|__|__|__|__|			|__|__|/|__|__|/|__|__|__|__|		
	|__|__|/|__|__|/|__|__|__|__|	|__|__|__|__|			|__|__|/|__|__|/|__|__|__|__|		

*Albendazole or Mebendazole or Amphotericin B or Others

** Side-effect within the 1st month of treatment

#5.2 – Antibiotics

Antibiotics ? O Yes O No

Name of the drug	Date of initiation	Date of withdrawal
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|

#5.3 – Other treatment

Other ? O Yes O No

Treatement	Date of initiation	Date of withdrawal
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|
…	|__|__|/|__|__|/|__|__|__|__|	|__|__|/|__|__|/|__|__|__|__|

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#6 – INTERVENTION

#6.1 – Radical surgery

Date : |__|__|/|__|__|/|__|__|__|__|

Hospital : _ Department : _

- **Open liver surgery :** O Yes O No
  - Hepatectomy : O Yes O No
    - Type of procedure :
      - ○ Segmental resection
      - ○ Left hemihepatectomy
      - ○ Right hemihepatectomy
      - ○ Extended hepatectomy
      - ○ Central resection
    - Biliary reconstruction : O Yes O No
    - Vascular reconstruction : O Yes O No
  - Liver allo-transplantation : O Yes O No
  - Liver auto-transplatation : O Yes O No
- **Laparoscopic liver surgery :** O Yes O No
- **Other type of surgery :** O Yes O No

Organ :

- ☐ lung
- ☐ liver
- ☐ central nervous system
- ☐ bone
- ☐ spleen
- ☐ diaphragm
- ☐ pancreas
- ☐ kidney
- ☐ adrenals
- ☐ pleura
- ☐ pulmonary system
- ☐ muscle
- ☐ organ lining
- ☐ member
- ☐ heart
- ☐ Abdominal wall, parietal muscles
- ☐ other localisation

#6.2 – Palliative intervention

Date : |__|__|/|__|__|/|__|__|__|__|

Hospital : _ Department : _

Open liver surgery : O Yes O No Per-cutaneous procedure (PCP) : O Yes O No

Laparoscopic surgery : O Yes O No Per-endoscopic procedure (PEP) : O Yes O No

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#7 – BIOLOGICAL DATA

#7.1 – Summary of biodata at diagnosis

Serology done : O Yes O No

If yes : Date : |__|__|/|__|__|/|__|__|__|__|

Result : O Positive O Negative

Test :
- ○ First line (Elisa, IHA, ...)
- ○ Second line (Western Blot)
- ○ Both

Tissue biopsy done : O Yes O No

If yes : Date : |__|__|/|__|__|/|__|__|__|__|

Organ :
- ☐ lung
- ☐ liver
- ☐ central nervous system
- ☐ bone
- ☐ spleen
- ☐ diaphragm
- ☐ pancreas
- ☐ kidney
- ☐ adrenals
- ☐ pleura
- ☐ pulmonary system
- ☐ muscle
- ☐ organ lining
- ☐ member
- ☐ heart
- ☐ Abdominal wall, parietal muscles
- ☐ other localisation

Histopathology examination : O Done O Not done

If done, Date : |__|__|/|__|__|/|__|__|__|__|

Result : O AE O Echinococcus O Non specific

Molecular identification : O Done O Not done

If done, Date : |__|__|/|__|__|/|__|__|__|__|

Result : O AE O Echinococcus O Non specific

Tissue cytology done : O Yes O No

If yes : Molecular identification : O Done O Not done

If done, Date : |__|__|/|__|__|/|__|__|__|__|

Result : O AE O Echinococcus O Non specific

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

#7.2 – Serology at diagnosis

Date : |__|__|/|__|__|/|__|__|__|__|

1st line tests (screening) :

Technique(s) bases on E granulosus antigen : Done : O Yes O No

Technique*	Manufacturer	Result	Cut off	Interpretation**
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	

Technique based on E multilocularis antigen : Done : O Yes O No

Technique*	Manufacturer	Result	Cut off	Interpretation**
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	

*Elisa or IHA or IFI or ICT or Other

**Negative or Positive or Equivocal

2nd line tests (confirmation) : Done : O Yes O No

Technique*	Manufacturer	Result	Cut off	Interpretation**
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	
		|__|__|__|__| , |__|__|__|	|__|__|__|__| , |__|__|__|	

*Western Blot or Immunoelectrophoresis or Other

** Negative or Positive or Equivocal

Is WB LBBio bands positive ? O Yes O No

7 kDa : O Yes O No
16 kDa : O Yes O No
17 kDa : O Yes O No
18 kDa : O Yes O No
26-28 kDa : O Yes O No

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/

Serology conclusion :

- ○ Positive, probably CE
- ○ Positive, probably AE
- ○ Echinococcus sp. Positive
- ○ Equivocal
- ○ Negative
- ○ Increased level of antibodies
- ○ Stable level of antibodies
- ○ Decreased level of antibodies
- ○ Negative serology

#7.3 – Biopsy at diagnosis

Done : O Yes O No

Date : |__|__|/|__|__|/|__|__|__|__|

Number of analyzed samples : |__|__|

Samples :

Sample origin*	Type of sample*	Histopathology result***	Immunohisto-chemistry result****	Molecular analysis sample*****	Molecular analysis result******

*Liver or Lung or Other organ/tissue
**Surgical or Non surgical sample
***AE or Parasitic disease or No parasite but necrosis or No parasite but granulomatous or No suspicion of echinococc.
****AE or Parasitic disease or No suspicion of echinococcosis
*****Non-preserved sample or FFPE tissue
******AE or Echinococcus sp. Or Note done

Tel. 03.70.63.23.50 – FAX 03.70.63.23.24
cnr-echino@chu-besancon.fr
https://cnr-echinococcoses-ccoms.univ-fcomte.fr/