

Japanese Biliary Atresia Registry (JBAR) Sheet 1/3 [Follow-up Year 1]

Target years for follow-up year 1: 1989~2017

Total number of initial registrations in target years: 3392

Number of deaths: 247

追跡1年目登録総数 : 2404例 (76.4 %)

Outcome with liver transplant		654	Outcome without liver transplant		1741	Unknown cases		9
Living		613	Living		1666	Living		4
Living without jaundice		541	Living without jaundice		1437	Living without jaundice		3
Living with jaundice		29	Living with jaundice		196	Living with jaundice		1
Unknown		43	Unknown		33	Unknown		0
Death		15	Death		69	Death		0
Unknown		26	Unknown		6	Unknown		5
Age at death (days)			Age at death (days)			Age at death (days)		
Minimum		387	Minimum		248	Minimum		ND
Maximum		801	Maximum		920	Maximum		ND
Mean		594.7	Mean		492.8	Mean		ND
Standard deviation		129.0	Standard deviation		157.9	Standard deviation		ND
Cause of death			Cause of death			Cause of death		
Liver failure		0	Liver failure		8	Liver failure		0
Rupture of esophageal varices		0	Rupture of esophageal varices		1	Rupture of esophageal varices		0
Pneumonia		1	Pneumonia		1	Pneumonia		0
Peritonitis		0	Peritonitis		0	Peritonitis		0
Sepsis after cholangitis		0	Sepsis after cholangitis		0	Sepsis after cholangitis		0
Post-transplantation death		4	Post-transplantation death		0	Post-transplantation death		0
Cause of death unknown		0	Cause of death unknown		2	Cause of death unknown		0
Other		10	Other		52	Other		0
(Includes duplications)			(Includes duplications)			(Includes duplications)		
NA		0	NA		0	NA		0

Japanese Biliary Atresia Registry (JBAR) Sheet 2/3 [Follow-up Year 1]

Target years for follow-up year 1: 1989~2017

Total number of initial registrations in target years: 3392

Number of deaths: 247

追跡1年目登録総数 : 2404例 (76.4 %)

3. Native liver survivors: liver function tests (sin)		4. Esophageal varices in cases without liver tran		7. Surgeries other than liver transplant (except for unknown cases)			
Number of liver function tests (implemented) 1043		Yes	300	Yes	181		
Total bilirubin (mg/dl)		(Duplications in treatment content)	No treatment	167	Hilar re-dissection	70	
Minimum	0.1		Treatment	121	Hilar curettage	20	
Maximum	61.0		Endoscopic treatment or sclerotherapy	111	Endoscopic hilar curettage	4	
Mean	1.1		Direct approach	0	Other	103	
Standard deviation	3.1		Shunt	1	Unknown	7	
ALT (IU/l)			Other	5	None	2103	
Minimum	2.9	Unknown	4	Unknown	112		
Maximum	786.0	Details of treatment unknown	12	8. Re-elevation of jaundice (except for unknown cases)			
Mean	68.8	None	689	Yes	553		
Standard deviation	71.1	Unknown	752	No	1733		
γGTP (IU/l)		5. Hypersplenism in cases without liver transplan		Unknown	109		
Minimum	7.0	Yes	289	If yes			
Maximum	1892.0	(Duplications in treatment content)	No treatment	270	Before	No jaundice	200
Mean	170.7		Treatment	4	re-elevation	Mild jaundice	136
Standard deviation	200.8		Partial splenic embolization	1	Cause of re-elevation (includes duplications)	Unknown	21
ChE (IU/l)			Splenectomy	0		Ascending cholangitis	379
Below normal range	172		Other	8		Other	99
Within normal range	721		Details of treatment unknown	1		Unknown	82
Unknown	150	Use of treatment unknown	16	Final measures	Monitor patient	47	
ALP (IU/l)		None	1298	(includes duplications)	Conservative treatment	313	
Above normal range	50	Unknown	154		Re-curative surgery	30	
Within normal range	943	6. Other complications (except for unknown cases)			Liver transplant	118	
Unknown	50	Cholangitis			Other	39	
		Gastrointestinal bleeding other than varices			Unknown	18	
		Ascites					
		Fat soluble vitamin deficiency					
		Intrahepatic cholelithiasis					
		Pulmonary hypertension					
		Hepatopulmonary syndrome					
		Intestinal obstruction					
		Other					
		(Includes duplications)					

Japanese Biliary Atresia Registry (JBAR) Sheet 3/3 [Follow-up Year 1]

Target years for follow-up year 1: 1989~2017

Total number of initial registrations in target years: 3392

Number of deaths: 247

追跡1年目登録総数 : 2404例 (76.4 %)

Outcome with liver transplant		654	Outcome without liver transplant		1741
9. Mental development			9. Mental development		
Excellent		8	Excellent		36
Normal		505	Normal		1510
Low		22	Low		69
Unknown		119	Unknown		126
10-1. Physical development			10-1. Physical development		
Excellent		7	Excellent		36
Normal		492	Normal		1484
Low		44	Low		117
Unknown		111	Unknown		104
10-2. Physical status			10-2. Physical status		
Height (cm)			Height (cm)		
	Minimum	68.0		Minimum	73.8
	Maximum	83.4		Maximum	76.0
	Mean	72.7		Mean	74.7
	Standard deviation	5.6		Standard deviation	1.2
Weight (kg)			Weight (kg)		
	Minimum	7.9		Minimum	8.7
	Maximum	12.2		Maximum	10.6
	Mean	9.4		Mean	9.6
	Standard deviation	1.6		Standard deviation	1.0

NB 10.2 Physical status is an aggregation of data collected from JBAR2016.