Fanconi Anemia Registry 01 after HSCT
FAR01 Follow up – 1 Year

Patient initials (first name / last name) |__|__|

Quarter and year of birth (q/yyyy) |__| / |__|__|__|__|

Sex: ☐ male ☐ female

Disease Status 1 Year after SCT or date of death

☐ CR ☐ Autologous reconstitution

☐ Relapse in the case of AML/MDS (date) I__I__II__I__II__I__I

site: ☐ BM ☐ PB ☐ other, specify_____

Treatment after SCT

☐ No ☐ Yes, please specify indication:

- ☐ relapse
- ☐ no remission
- ☐ mixed chimerism
- ☐ graft failure
- ☐ GVHD
- ☐ Viral infection
- ☐ EBV induced lymphproliferation
- ☐ prophylactic treatment
- ☐ other: |_____|

If yes, kind of treatment:

- ☐ reduction or discontinuation of immunosuppression
- ☐ chemotherapy
- ☐ donor leukocyte infusion

1.DLI: no. of CD3 or CD|__| cells: |___| /kg x10E |__| |__|__||__|__||__|__| (dd/mm/yy)
2.DLI: no. of CD3 or CD|__| cells: |___| /kg x10E |__| |__|__||__|__||__|__| (dd/mm/yy)
3.DLI: no. of CD3 or CD|__| cells: |___| /kg x10E |__| |__|__||__|__||__|__| (dd/mm/yy)
4.DLI: no. of CD3 or CD|__| cells: |___| /kg x10E |__| |__|__||__|__||__|__| (dd/mm/yy)

other type of infusion:

- ☐ MNC cells: number: |__|__| ☐ dentritic cells: number: |__|__|
- ☐ mesenchymal cells: number: |__|__| ☐ NK cells: number: |__|__|
- ☐ antigen specific T-cells: number: |__|__| ☐ fibroblasts: number: |__|__|
- ☐ stem cell boost (CD 34+ pos.selec.) number: |_____| /10^6kg
  Date : |__|__| |__|__| |__|__| (dd/mm/yy)
- ☐ subsequent SCT Date of SCT:|__|__| |__|__| |__|__| (dd/mm/yy)
  type of transplant: ☐ auto ☐ allo

Chimerism

Best Chimerism after day +100:

PB/BM	Date	% of Donor cells	Method
|_____|	|__|__||__|__||__|__|	|_____|	|_____|

Chronic GvHD

☐ No ☐ Yes, date of onset: |__|__| |__|__| |__|__| (dd/mm/yy)

☐ Classic chronic GvHD

☐ Overlap syndrom of acute/chronic GvHD

Staging	Score	Score 1	Score 2	Score 3	n.d.
Lansky/ Karnofski	100%	80-90%	60-70%	< 60%	☐
Skin	No Symptoms	<18% BSA with disease signs but NO sclerotic features	9-50% BSA OR involvement with superficial sclerotic features, "not hide-bound" (able to pinch)	>50% BSA OR deep sclerotic features "hidebound" (unable to pinch) OR impaired mobility, ulceration or severe puritus	☐
Mouth	No Symptoms	Mild symptoms with disease signs but not limiting oral intake significantly	Moderate symptoms with disease signs with partial limitation of oral intake	Severe symptoms with disease signs on examination with major limitation of oral intake	☐
Eyes	No Symptoms	Mild dry eye symptoms not affecting ADL (requiring eyedrops = 3 x per day) OR asymptomatic signs of keratoconjunctivitis sicca	Moderate dry eye symptoms partially affecting ADL (requiring eyedrops >3 x per day or punctual plugs), without vision impairment	Severe dry eye symptoms significantly affecting ADL (special eyeware to relieve pain) OR unable to work because of ocular symptoms OR loss of vision caused by eratoconjunctivitis sicca	☐
GI Tract	No Symptoms	Symptoms such as dysphagia, anorexia, nausea, vomiting, abdominal pain or diarrhea without significant weight loss (< 5%)	Symptoms associated with mild to moderate weight loss (5-15%)	Symptoms associated with significant weight loss >15%, requires nutritional supplement for most calorie needs OR esophageal dilation	☐
Lungs	No Symptoms	Mild symptoms (shortness of breath after climbing one flight of steps) OR FEVI 60-79%	Moderate symptoms (shortness of breath after walking on flat ground) OR FEVI 40-59%	Severe symptoms (shortness of breath at rest; requiring O2) OR FEVI = 39%	☐
Liver	No Symptoms	Elevated Bilirubin, AP*, AST or ALT <2 x ULN	Bilirubin >3 mg/dl or Bilirubin, enzymes 2-5 x ULN	Bilirubin or enzymes > 5 x ULN	☐
Joints and Fascia	No Symptoms	Mild tightness of arms or legs, normal or mild decreased range of motion (ROM) AND not affecting ADL	Tightness of arms or legs OR joint contractures, erythema thought due to fasciitis, moderate decrease ROM AND mild to moderate limitation of ADL	Contractures WITH significant decrease of ROM AND significant limitation of ADL (unable to tie shoes, button shirts, dress self etc.)	☐
Genital Tract	No Symptoms	Symptomatic with mild signs on exam AND no effect on coitus and minimal discomfort with gynecologic exam	Symptomatic with moderate signs on exam AND with mild dyspareunia or discomfort with gynecologic exam	Symptomatic WITH advanced signs (stricture, labial agglutination or severe ulceration) AND severe pain with coitus or inability to insert vaginal speculum	☐
Overall Grade	No Symptoms	Mild	Moderate	Severe	☐

Staging according to classical definition

☐ limited
☐ extended

Resolution of cGvHD in same period of documentation

☐ No
☐ yes, Date of cGvHD resolution |__|__| |__|__| |__|__| (dd/mm/yy)

Complications 1 Year after SCT of death respectively

Severe complications:		no yes
pulmonary	radiologic changes and/or oxygen support	☐ ☐
	mechanical ventilation	☐ ☐
cardio vascular	shortening fraction < 25%	☐ ☐
	inotropic support with catecholamines	☐ ☐
	anti-arrhythmic therapy	☐ ☐
renal	relevant creatinine elevation (>CTCAE grade 2)	☐ ☐
	hemodialysis or hemofiltration	☐ ☐
	Fanconi syndrom	☐ ☐
	nephrotic syndrom	☐ ☐
hepatic	relevant bilirubine elevation (>CTCAE grade 2)	☐ ☐
neurological	leukencephalopathy	☐ ☐
	CNS hemorrhage	☐ ☐
	seizures	☐ ☐
gastrointestinal	Ileus	☐ ☐
	gastrointestinal hemorrhage	☐ ☐

Infectious Toxicity

Date of infection: |__|__| |__|__| |__|__| (dd/mm/yy)

Clinical type of infection:
- ☐ viral
- ☐ bacterial
- ☐ fungal
- ☐ parasitic

Site
- ☐ systemic
- ☐ localized: ☐ respiratory tract ☐ GI tract ☐ CNS ☐ urogenital tract ☐ other, specify: |_____|

Pathogen identified

☐ No ☐ Yes

Viral infection pathogen
- ☐ CMV
- ☐ EBV
- ☐ Adenovirus
- ☐ other, specify:|_____|

Status CMV infection
- ☐ infection
- ☐ disease

Status EBV infection
- ☐ infection
- ☐ PTLD

Fungal infection pathogen
- ☐ Aspergillus
- ☐ Candida
- ☐ other, specify:|_____|

Other clinically significant coexisting disease or organ impairment:

☐ No ☐ Yes, please specify:

- ☐ severe bleeding
- ☐ infarction or thrombosis
- ☐ VOD
- ☐ ARDS
- ☐ acute vascular leak syndrome

Intensive care measures:

☐ No ☐ Yes, please state indication:

- ☐ assisted ventilation
- ☐ hemodialysis
- ☐ hemofiltration
- ☐ other: |_____|

Graft Failure:

☐ No ☐ Yes, date of diagnosis |__|__| |__|__| |__|__| (dd/mm/yy)

Status at 1 Year after SCT

Disease status:

☐ CR ☐ Autologous reconstitution

☐ Relapse in the case of AML/MDS (date) I__I__II__I__II__I__I

site: ☐ BM ☐ PB ☐ other, specify_____

☐ Secondary malignancy ☐ No ☐ Yes, date of diagnosis |__|__| |__|__| |__|__| (dd/mm/yy)

specified:|_____|

Survival status:

☐ Alive date last examination (dd/mm/yy) I__I__II__I__II__I__I Karnofsky/ Lansky score I_____I %

☐ Dead date of death (dd/mm/yy) I__I__II__I__II__I__I Autopsie ☐ no ☐ yes

Main cause of death:

- ☐ Underlying disease: Relapse, progression or persistence
- ☐ Transplant related cause (tick all that apply):
  - ☐ GVHD
  - ☐ graft failure
  - ☐ pulmonary toxicity
  - ☐ cardiac toxicity
  - ☐ infection
  - ☐ VOD
  - ☐ post transplant lymphoproliferative disorder
  - ☐ other: |_____|
- ☐ other: |_____|

☐Other, specify _____

Further comments: _____

Referring physician name and institution I_____I

Address I_____I

Telephone and fax I_____I

email I_____I

Date I__I__II__I__II__I__I Signature _____