Thalassaemics Diary

A clinical record book for thalassaemia patients

Patient Name: _____

THALASSAEMIA FEDERATION OF PAKISTAN

Family Data

1. Name.....
2. Date of Birth.....Age.....
3. First Transfusion.....
4. Father's name.....
5. CNIC.....
6. Mother's name.....
7. CNIC.....
8. Contact No.....Address.....

   .....
9. Number of children.....
10. Thalassaemia Reg. No.....Blood Group.....
11. Number of traits.....
12. Number of thalassaemics.....
13. Area of residence - Rural ☐ Urban ☐ Peri-urban ☐

    Socio Economic Status - Poor ☐ Avg. ☐ Good ☐
14. Number of years residence in the area.....
15. Number of siblings dead.....
16. Father's occupation.....
17. Yearly family income.....

Pedigree

Immunization History

1. EPI - Complete/Partial/None
2. Hepatitis B vaccination on.....
3. Pneumonia vaccination on.....
4. Influenza vaccination on.....
5. Typhoid vaccination on.....
6. .....
7. .....

Puberty History-

Menstrual History- (For female)

Physical Examination
&
Growth Monitoring

Physical Examination

Growth Monitoring

Date	Skin Pigmen.	Pallor	Jaundice	Edema	Pulse	BP	Liver cm	Spleen cm	Height cm	Weight kg	Wt/Age	Wt/Ht	Ht/Age	Doctor Sign

Physical Examination

Growth Monitoring

Date	Skin Pigmen.	Pallor	Jaundice	Edema	Pulse	BP	Liver cm	Spleen cm	Height cm	Weight kg	Wt/Age	Wt/Ht	Ht/Age	Doctor Sign

Physical Examination

Growth Monitoring

Date	Skin Pigmen.	Pallor	Jaundice	Edema	Pulse	BP	Liver cm	Spleen cm	Height cm	Weight kg	Wt/Age	Wt/Ht	Ht/Age	Doctor Sign

Transfusion History
&
Transfusion Treatment

Transfusion started on.....

Total Number of transfusion so far.....

Pattern - Regular/Irregular

Pre transfusional Hemoglobin level maintained on.....gm

4. Usual Interval between transfusion.....
5. Recommended blood product.....
6. Reaction.....
7. Any Special note.....

Transfusion Treatment

Date	No. of Blood Unit	Unit Type	HCT	Transfused Pure RBC		Reaction	Hemoglobin				Hb Fall			Interval Days	Next Trans. Date	Note & Sign
							Pre		Post							
				Amount	ml/kg Body Weight		Date	Hb	Date	Hb	Observed	%	Expected			

Transfusion Treatment

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							Pre		Post							
				Amount	ml/kg Body Weight		Date	Hb	Date	Hb	Observed	%	Expected			

Iron Chelation Schedule

Iron Chelation Schedule

Clinical & Laboratory Evaluation (Monthly)

Clinical & Laboratory Evaluation (Yearly)

Doctor's Note

Chelation Calendar

Annual Summary Chart

Clinical & Laboratory Evaluation Checklist

Date	Presc. days	Desferal								Deferasirox/Deferiprone						Note	Reaction
		Infusion Type	Total gm/day	Conc. %	mg/ kg/ day	Vit. C	Infusions			Compl-iance	Tot. gm/day	mg/kg/ day	Presc. day/week	Tab. consumed	Expec-ted	Compl-iance		
							Presc. no./ week	Expected	Done									

Iron Chelation Schedule

		Desferal									Deferasirox/Deferiprone							
Date	Presc. days	Infusion Type	Total gm/day	Conc. %	mg/kg/day	Vit. C	Infusions			Compliance	Tot. gm/day	mg/kg/day	Presc. day/week	Tab. consumed	Expected	Compliance	Note	Reaction
							Presc. no./week	Expected	Done									

Clinical & Laboratory Evaluation (Monthly)

Clinical & Laboratory Evaluation (Monthly)
Clinical & Laboratory Evaluation (Yearly)
Doctor's Note
Chelation Calendar
Annual Summary Chart
Clinical & Laboratory Evaluation Checklist

Complete Blood Count (CBC)

Date	Hb gm	TLCx1000	N %	L %	M %	Platelet x 1000	HCT	ANC	Note

Clinical and Laboratory Evaluation (Monthly)
Complete Blood Count (CBC)

Date	Hb gm	TLCx1000	N %	L %	M %	Platelet x 1000	HCT	ANC	Note

Clinical and Laboratory Evaluation

Date	Body Iron Evaluation		Liver Function Evaluation					Renal Function Evaluation		Doctor's Note
	Ferritin	CRP	ALT	AST	PT	Glucose	Total Bill.	Urea	Creatinine	

Clinical and Laboratory Evaluation

Date	Body Iron Evaluation		Liver Function Evaluation					Renal Function Evaluation		Doctor's Note
	Ferritin	CRP	ALT	AST	PT	Glucose	Total Bill.	Urea	Creatinine	

Clinical & Laboratory Evaluation (Yearly)

Clinical & Laboratory Evaluation (Yearly)
Doctor's Note
Chelation Calendar
Annual Summary Chart
Clinical & Laboratory Evaluation Checklist

Clinical and Laboratory Evaluation (Yearly)

Virology

Date	HAV IgM	Hep B panel					Hep C panel		Anti HBE	Anti HIV (1+2)
		HBsAg	Anti HBs	Anti HBc IgM	Anti HBe	HBV DNA	Anti HCV	HCV RNA		

Bone Examination
ABD USG

Liver Biopsy	Ophthalmology Examination	Audiology Examination
☐ Liver Iron concentration- ☐ Histology		

Clinical and Laboratory Evaluation (Yearly)

Endocrine Function Evaluation (Yearly)

Date / Test			
T3			
T4			
TSH			
Parathyroid			
LH			
FSH			
Testosterone			
Estrogen			
Progesterone			
Estradiol			
OGTT (F / PP)			
Bone Age			
Bone Density			

Result of any special test indicated -

Vaccination-

Vaccine	Date	Date	Date	Date
Hepatitis B				
Pneumococcal				
Meningococcal				
Splenectomy Done				

Doctor's Note

Doctor's Note

Date	Date

Date

Date

Chelation Calendar

Chelation Calendar

Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
JAN																															
FEB																															
MAR																															
APR																															
MAY																															
JUN																															
JUL																															
AUG																															
SEP																															
OCT																															
NOV																															
DEC																															

Use the above calendar to keep a record of your chelation
For Example: Use Red for Desferal days Use Blue for Deferiprone days Use Green for combination days Use Orange for Deferasirox
Remember don't cheat?
Adapted from: PATIENT held record final v3.doc, U.K. Thalassaemia Society

Clinical and Laboratory Evaluation

Bone Density Record (DEXA scan yearly from age 10)

Date	Site of Bone pain/fracture	DEXA Spine bone mineral density (Z acore)	DEXA Hip bone mineral density (Z acore)	Hormone replacement treatment (Drug and dose)	Bisphosphonate treatment (Drug and dose)	Comments

Annual Summary Chart

Annual Summary Chart

Year	Age Yrs	Total Blood Units	Mean Req ml/ kg/day	Splene-ctomy	Mean Hb gm/dl			Hb Fall %	Iron balance				Mean compli-ance	Ferritin			Mean ALT	Clinical Note & Sign
					Pre	Post	Mean		In		Out			Min	Max	Mean		
									Total mg	mg/kg /day	Total mg	mg/kg/ day						

Equations

Transfusion Treatment Chart

$$\text{Hb Post} = \text{Hb pre} + \frac{\text{Transfused amount of pure RBC}}{\text{Average index of last six month}}$$

$$\text{Index} = \frac{\text{Transfused amount of pure RBC}}{\text{(Hb post - Hb pre)}}$$

$$\text{Observed Hb fall} = \frac{\text{(Previous Hb post - Hb pre)}}{\text{Transfusion Interval}}$$

$$\%\ \text{Hb fall} = \frac{\text{Observed Hb fall x 100}}{\text{Previous Hb post}}$$

$$\text{Next Appointment} = \frac{\text{(Hb post - Hb pre desired)}}{\text{Expected Hb fall}} + \text{Previous date of transfusion}$$

$$\text{Hb fall expected} = \text{Post Hb - Hb pre desired}$$

Average 2.1 ml/kg is required to increase hemoglobin by 1gm/dl

Annual Summary Chart

$$\text{Desferal Compliance} = \frac{\text{Infusion Done}}{\text{Expected Infusion}} \times 100$$

$$\text{Desferal Compliance} = \frac{\text{Capsule Taken}}{\text{Expected Intake}} \times 100$$

Annual Summary Chart

$$\text{Mean Hb} = \frac{\Sigma\text{Hb pre} + \Sigma\text{Hb post}}{\text{(number of Hb pre + number of Hb post)}}$$

$$\text{Iron} = \text{Transfused amount of pure RBC} \times 1.16$$

$$\text{Iron out by Desferal} = \frac{\Sigma\text{(Infusion number x sideruria)} + \text{Iron excreted with intensive chelation}}{}$$

$$\text{Excreted Iron by L1} = \frac{\Sigma\text{(administration number x sideruria)}}{\text{Prescribed daily mean administration}}$$

اسُنرا کس طرح لی جائے؟

گولیاں ڈاکٹر کی ہدایت کے مطابق استعمال کریں۔ گولیاں ۱۰۰ اور ۴۰۰ ملی گرام میں دستیاب ہیں۔ دوا کی مقدار کا تعین آپ کا ڈاکٹر خود کرے گا جو یا تو ۱۰۰ ملی گرام یا ۴۰۰ ملی گرام کی گولی یا دونوں پر مشتمل ہوسکتی ہے۔ یہ انتہائی ضروری ہے کہ آپ دوا روزانہ ڈاکٹر کے نسخے کے مطابق استعمال کریں۔

گولی / گولیاں ۱۰۰ یا ۲۰۰ ملی لیٹر پانی میں ڈالیں۔

گولی / گولیاں مکمل طور پر حل ہونے تک ہلائیں۔
گلاس میں موجود محلول دودھیا مائل نظر آئے گا دودھیا مائل کا مطلب یہ ہے کہ دوا اس میں مکمل طور پر حل ہو چکی ہے۔

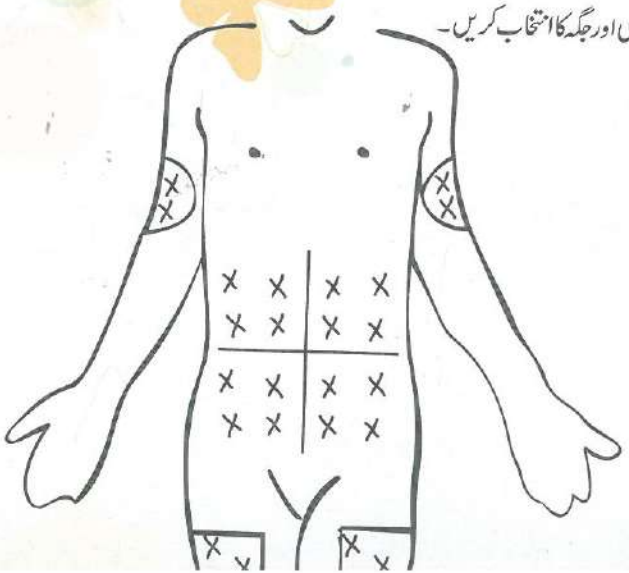
گلاس میں موجود تمام دوا پی لیں، پھر گلاس میں تھوڑا سا پانی ڈال کر ہلائیں اور یہ بھی پی لیں۔ یہ ضروری ہے کہ آپ سب کچھ پی لیں کیونکہ اسی طرح آپ دوا کی درست مقدار لے سکتے ہیں۔

■ گولیوں کو مشروبات یا دودھ میں حل مت کریں

ڈیسفرال انجیکشن کس طرح لیا جائے؟

مندرجہ ذیل تصویر ڈیسفرال انجیکشن لگانے کے لیئے مناسب جگہوں کی نشاندہی کر رہی ہے۔ انجیکشن لگاتے وقت اس بات کا خیال رکھیں کہ ہر بار انجیکشن لگانے کی جگہ تبدیل کریں تاکہ کسی بھی ممکنہ ری ایکشن یا انفیکشن سے بچا جا سکے۔

نیچے دی گئی تصویر کی جتنی چاہیں فوٹو کاپی کرائیں۔ جس جگہ آپ انجیکشن لگا چکے ہیں اس پر نشان لگائیں اور اگلی مرتبہ کسی اور جگہ کا انتخاب کریں۔



Clinical & Laboratory Evaluation Checklist

Clinical & Laboratory Evaluation Checklist

Clinical and Laboratory Evaluation Checklist

Monthly

- ☐ CBC

Every 6 month

Serum Iron Evalution

- ☐ Ferritin
- ☐ Iron
- ☐ TIBC

As Required

Liver Function Evaluation

- ☐ ALT/SGPT
- ☐ AST/SGOT
- ☐ Alkaline Phosphatase
- ☐ Glucose

Renal Function Evaluation

- ☐ Urea
- ☐ Creatinine

Every 6 months

Cardiac Evaluation

- ☐ Cardiac Echo
- ☐ EKG
- ☐ Heart chamber dimensions
- ☐ Systolic function
- ☐ Diastolic function
- ☐ Fractional shortening

Yearly

Virology

- ☐ Hepatitis C panel (anti-HCV, anti- HCV RIBA)
- ☐ Hepatitis B panel (HBsAg,anti-HBs,anti-HBc lgG)
- ☐ anti-HIV 1+2

Yearly

Endocrine Function Evaluation

- ☐ Free T4 & TSH
- ☐ Parathyroid
- ☐ FSH
- ☐ LH
- ☐ Testosterone
- ☐ Estradiol
- ☐ OGTT
- ☐ Bone age and bone density
- ☐ Zinc, Vit-C, Vit-E

Complete physical examination Opthalmology examination Audiology examination

As Indicated

As Indicated

- ☐ 24 - hour Holter monitor
- ☐ anti - HBc igM
- ☐ anti - HBe
- ☐ HBeAg
- ☐ anti-HDV
- ☐ HCV-RNA

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