

COMMUNITY CONTROL PROGRAMME CENTRE



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(M.Sc., Ph.D.)

**Emeritus Medical Scientist
Maharashtra Arogya Mandal
Hadapsar, Pune, M.S.**

**Former Professor & HOD of Biochemistry,
Deputy Director**

**Tribal Health Research Project
Dept. of Pediatrics, B.J. Medical College,
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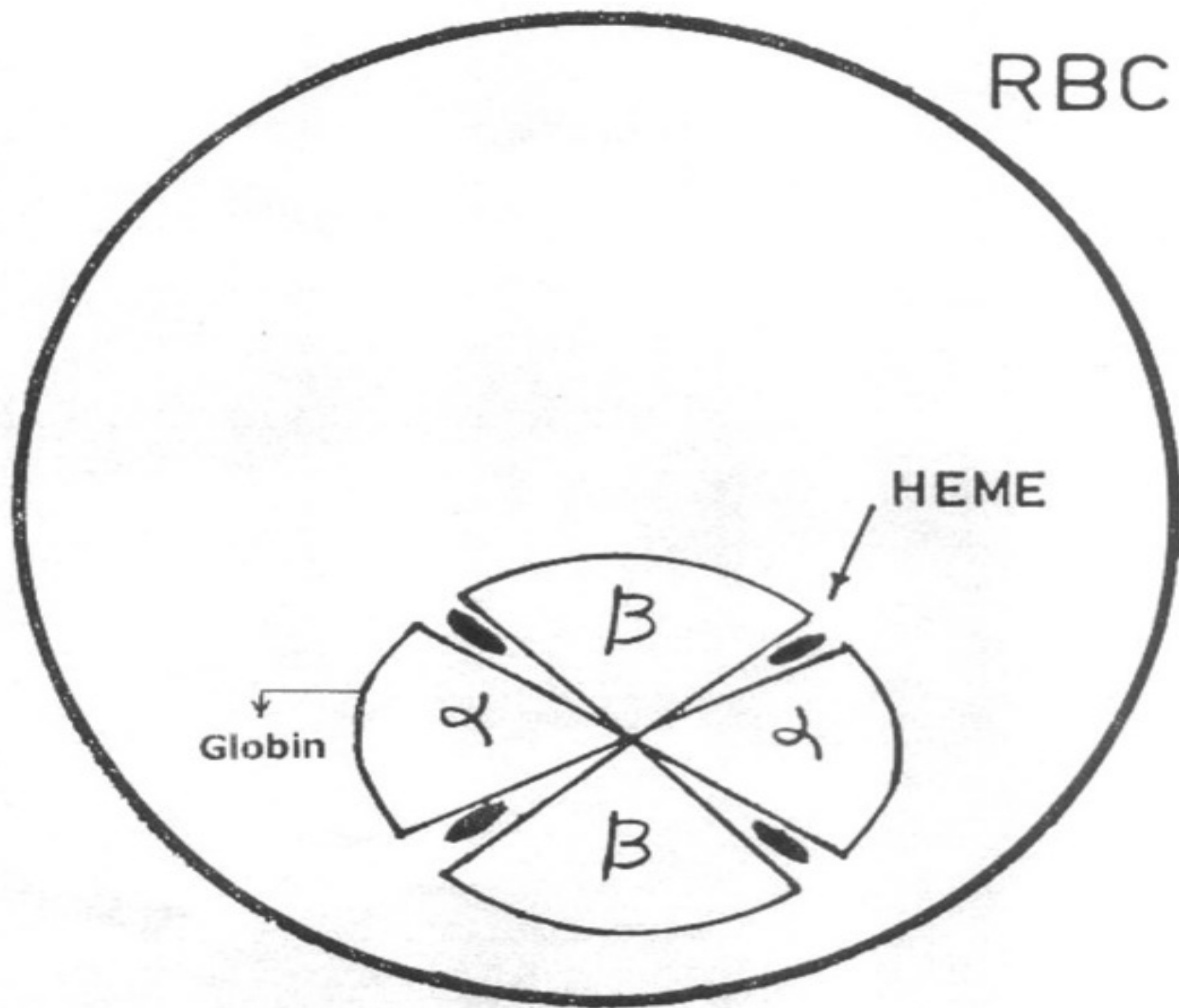
-: Office :-

**HOD- Sickle Cell Dept
Sane Guruji Arogya Kendra,
Malwadi, Hadapsar, Pune 411028**



Red Blood Cells





RBC

HEME

Globin

Hemoglobin Molecule

Mutation in Sickle Hemoglobin



Sickle : Origin of the name

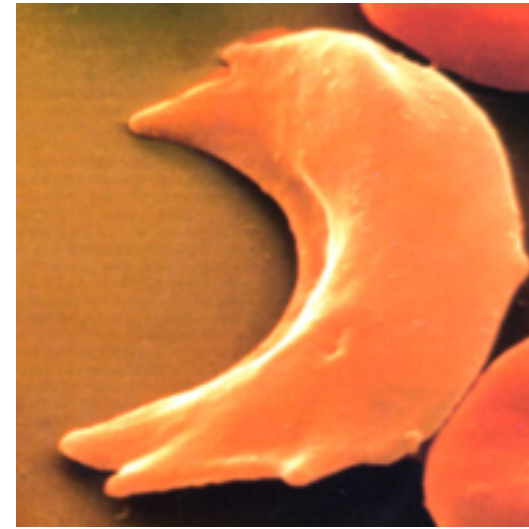


The name is derived from the shape of red blood cell which is like a sickle, the tool use for grass cutting

About Sickle Cell Disorder

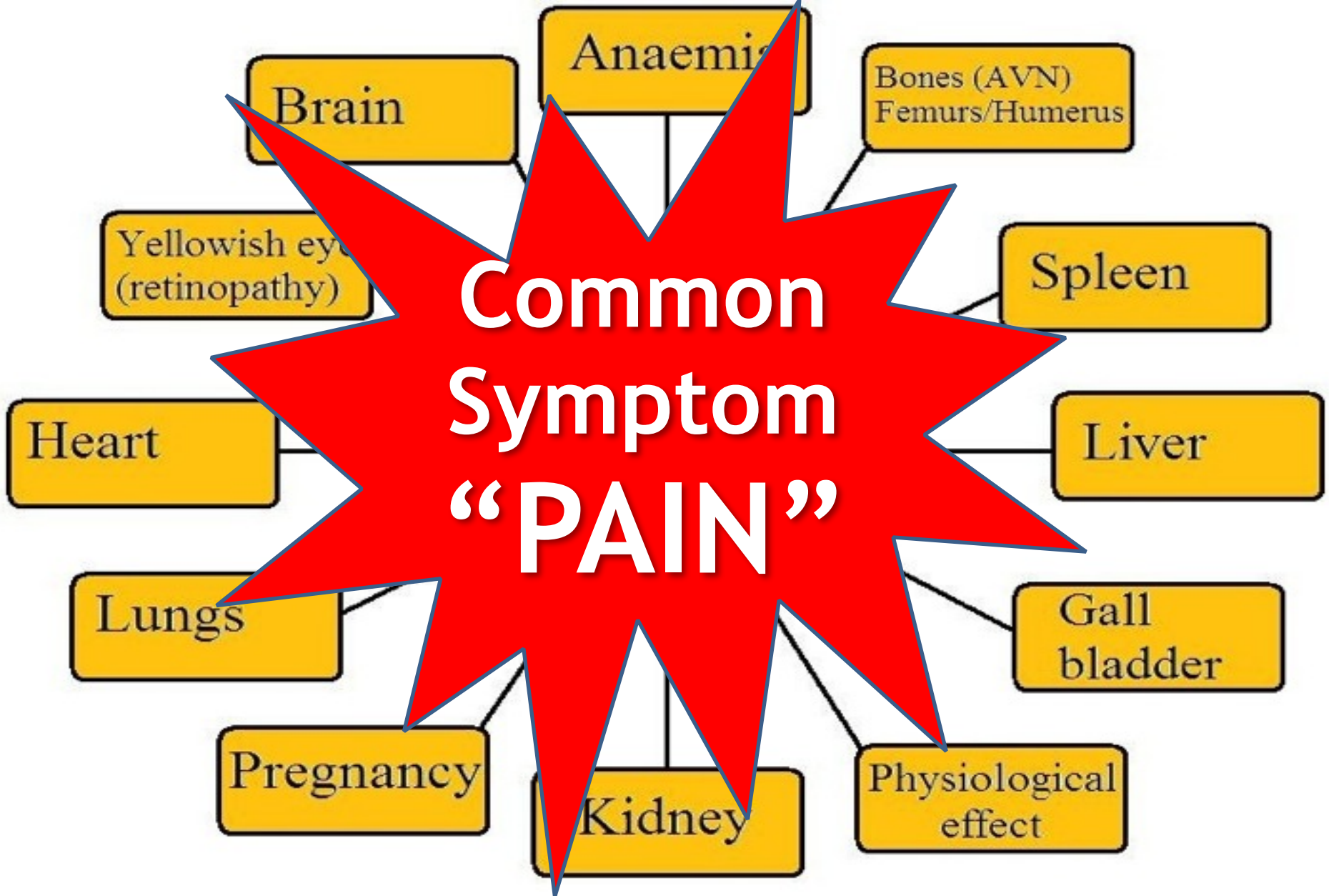


**Normal
Shaped RBC**



**Sickle
Shaped RBC**

Transformation of RBC from Round Shape to Sickle cell shape is known as sickling process
These sickled RBC get early destructed, leading to anaemia known as sickle cell anaemia
Factor responsible for this process is Sickle Cell Haemoglobin Molecule



**Basic Sickle cell hemoglobin genetic defect
not only give rise to anaemia but affect all organs**

Last 65 years studies emerge out following observations :

- ✓ It affect all part of the body but does not affect every patient in the same way.
- ✓ Differ widely from individual to individual
- ✓ Differ in both extent of complications & severity

Clinical Findings

Common :

Anaemia, Jaundice(yellowish ting in eye), Joint pain

- Splenomegaly
- Hepatomegaly
- Gallbladder stones
- Avascular necrosis of femoral head
- Acute chest syndrome
- Hand - Foot syndrome(in children only)
- Stork
- Crisis -

vaso-occlusive crisis

Very painful

Majority 3-4 times year

Sometime medical emergency

May succumb to death

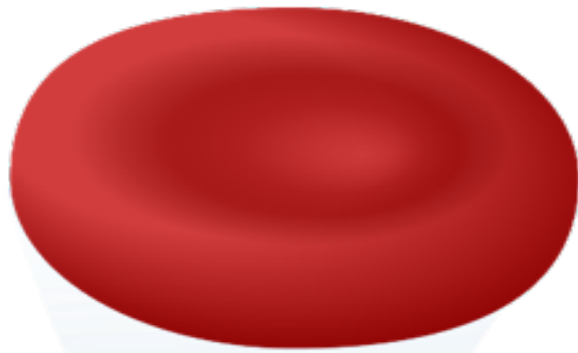
- Lea ulceration (Not recorded)
- Priapism (Not recorded)
- Retinal changes (Not Found)



Healthy

CRISIS

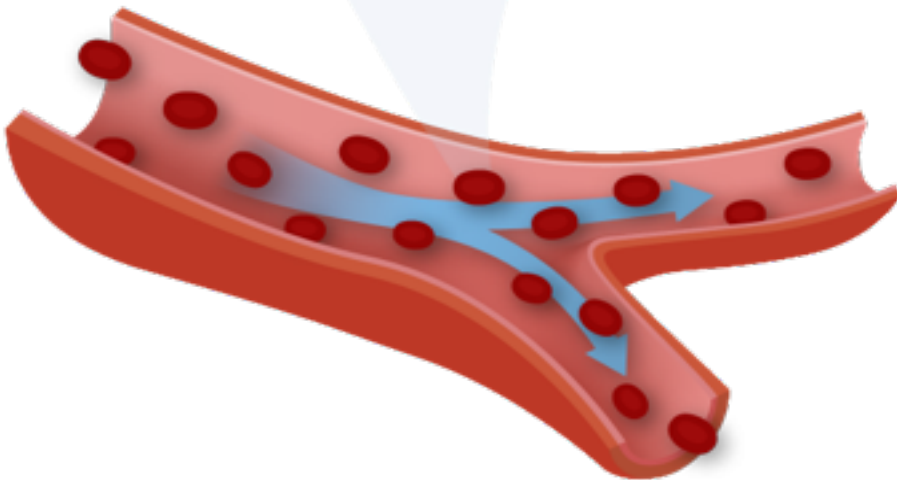
Sickle cell anaemia



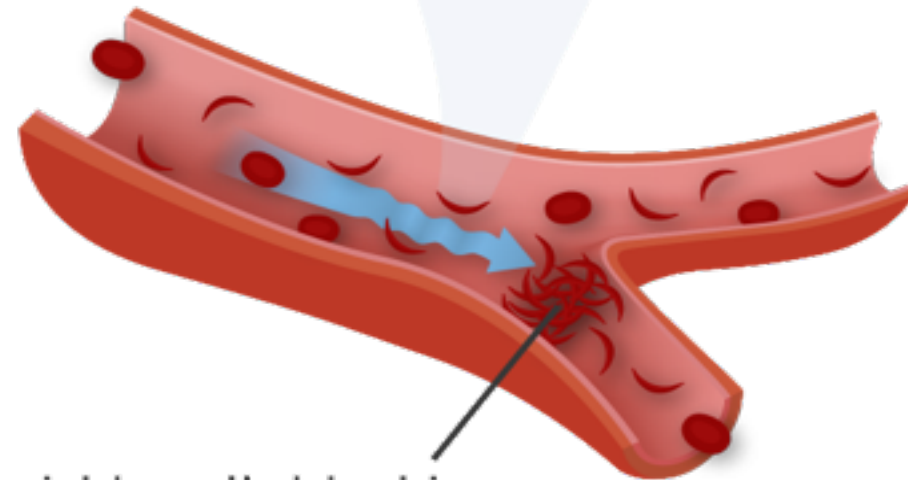
Normal red blood cell



Sickle red blood cell



unrestricted blood flow



sickle cells blocking
blood flow

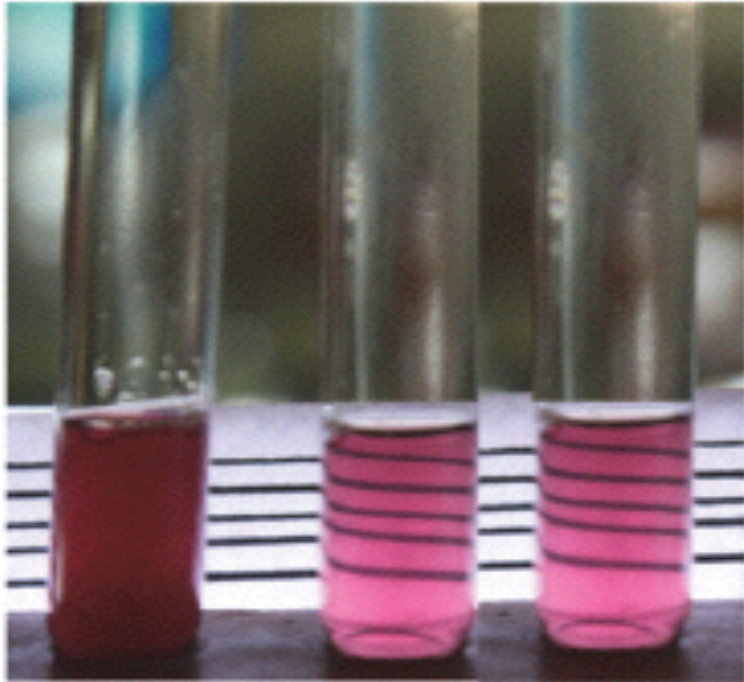
: Diagnosis :

- Haemoglobin
- Haemogram
- Smear studies
- Solubility test
- Electrophoresis
- Family studies
- HPLC studies

(Doubtful cases)

Laboratory diagnostic criteria - Blood test

Solubility Test

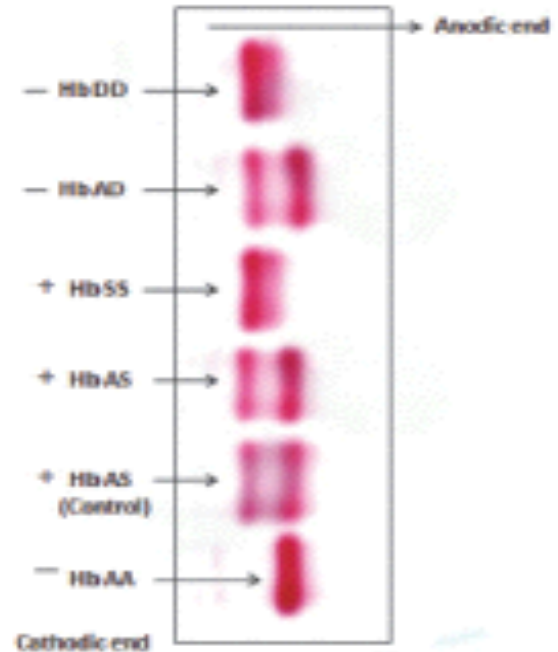


Positive control

Negative control

Negative sample

Cellulose Acetate Membrane Hb Electrophoresis at Alkaline pH 8.6



Solubility test
Sickle Cell status

Electrophoresis pattern

Negative
Positive

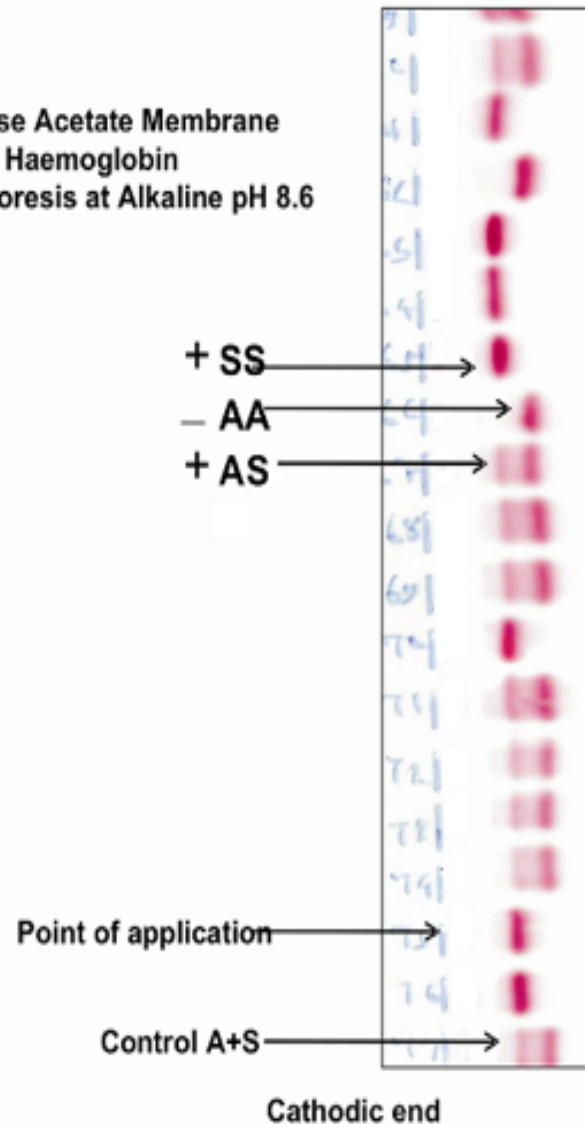
A+A
A+S

Normal
Carrier

Cellulose Acetate Membrane Electrophoresis (at alkaline pH 8.6)

Figure nos

Cellulose Acetate Membrane
Haemoglobin
Electrophoresis at Alkaline pH 8.6



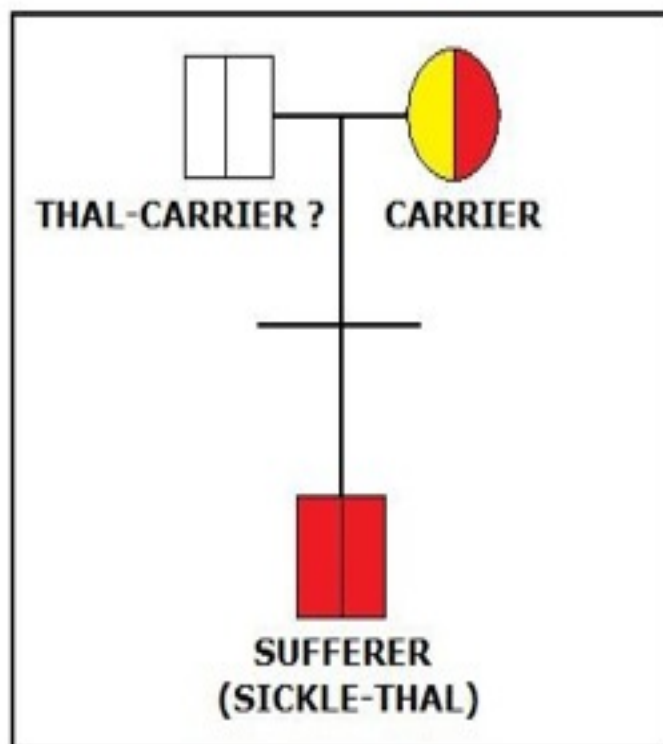
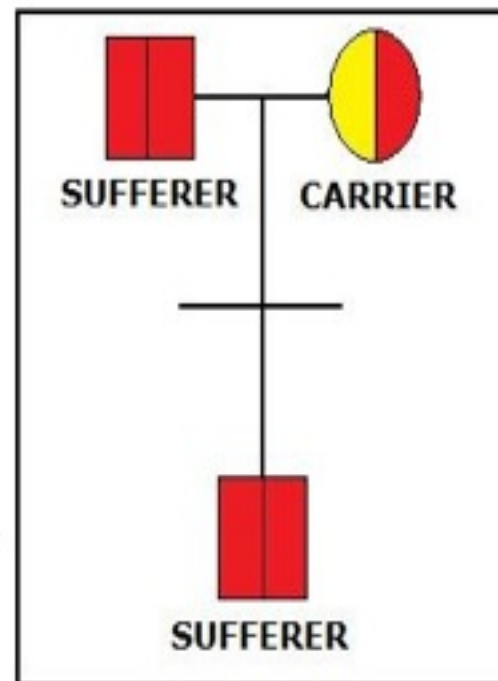
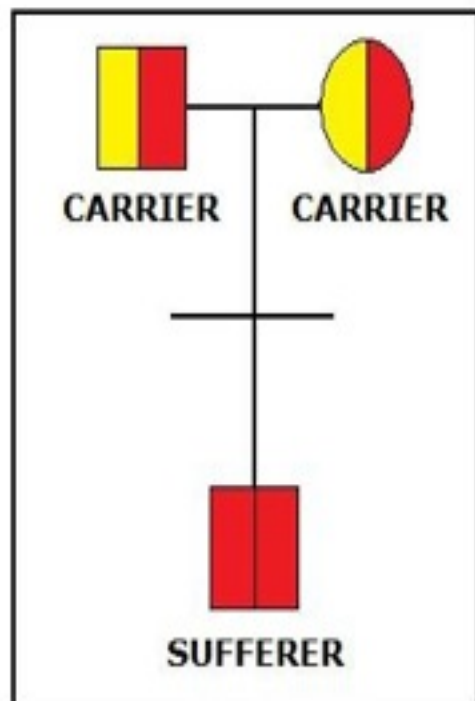
SICKLE CELL STATUS IDENTITY CARDS

- | | | |
|---|--------------------------------------|----------------------|
| नाम (Name) _____ | | सर्वप्रथम क्र. _____ |
| प्रीति/पुष्प : _____ | सम : _____ | वर्ग : _____ |
| पता : _____ | पता : _____ | पता : _____ |
| बरेल लैबोरेटरी | | |
| एनालीसिस प्र. नं. _____ | | विभाग : _____ |
| सिक्का केस नं. _____ | : (संश्लेषण/परीक्षण) Negative | |
| संश्लेषण/परीक्षण/विभाग : _____ | : A + A Pattern | |
| (सिक्का/परीक्षण/पता) | | |
| सिक्का केस (संश्लेषण/परीक्षण) : _____ | : सिक्का/परीक्षण/पता | |
| Address : Family Station, H.P.C. Station
101/102/103/104/105/106/107/108/109/110/111/112/113/114/115/116/117/118/119/120/121/122/123/124/125/126/127/128/129/130/131/132/133/134/135/136/137/138/139/140/141/142/143/144/145/146/147/148/149/150/151/152/153/154/155/156/157/158/159/160/161/162/163/164/165/166/167/168/169/170/171/172/173/174/175/176/177/178/179/180/181/182/183/184/185/186/187/188/189/190/191/192/193/194/195/196/197/198/199/200/201/202/203/204/205/206/207/208/209/210/211/212/213/214/215/216/217/218/219/220/221/222/223/224/225/226/227/228/229/230/231/232/233/234/235/236/237/238/239/240/241/242/243/244/245/246/247/248/249/250/251/252/253/254/255/256/257/258/259/260/261/262/263/264/265/266/267/268/269/270/271/272/273/274/275/276/277/278/279/280/281/282/283/284/285/286/287/288/289/290/291/292/293/294/295/296/297/298/299/300/301/302/303/304/305/306/307/308/309/310/311/312/313/314/315/316/317/318/319/320/321/322/323/324/325/326/327/328/329/330/331/332/333/334/335/336/337/338/339/340/341/342/343/344/345/346/347/348/349/350/351/352/353/354/355/356/357/358/359/360/361/362/363/364/365/366/367/368/369/370/371/372/373/374/375/376/377/378/379/380/381/382/383/384/385/386/387/388/389/390/391/392/393/394/395/396/397/398/399/400/401/402/403/404/405/406/407/408/409/410/411/412/413/414/415/416/417/418/419/420/421/422/423/424/425/426/427/428/429/430/431/432/433/434/435/436/437/438/439/440/441/442/443/444/445/446/447/448/449/450/451/452/453/454/455/456/457/458/459/460/461/462/463/464/465/466/467/468/469/470/471/472/473/474/475/476/477/478/479/480/481/482/483/484/485/486/487/488/489/490/491/492/493/494/495/496/497/498/499/500/501/502/503/504/505/506/507/508/509/510/511/512/513/514/515/516/517/518/519/520/521/522/523/524/525/526/527/528/529/530/531/532/533/534/535/536/537/538/539/540/541/542/543/544/545/546/547/548/549/550/551/552/553/554/555/556/557/558/559/560/561/562/563/564/565/566/567/568/569/570/571/572/573/574/575/576/577/578/579/580/581/582/583/584/585/586/587/588/589/590/591/592/593/594/595/596/597/598/599/600/601/602/603/604/605/606/607/608/609/610/611/612/613/614/615/616/617/618/619/620/621/622/623/624/625/626/627/628/629/630/631/632/633/634/635/636/637/638/639/640/641/642/643/644/645/646/647/648/649/650/651/652/653/654/655/656/657/658/659/660/661/662/663/664/665/666/667/668/669/670/671/672/673/674/675/676/677/678/679/680/681/682/683/684/685/686/687/688/689/690/691/692/693/694/695/696/697/698/699/700/701/702/703/704/705/706/707/708/709/710/711/712/713/714/715/716/717/718/719/720/721/722/723/724/725/726/727/728/729/730/731/732/733/734/735/736/737/738/739/740/741/742/743/744/745/746/747/748/749/750/751/752/753/754/755/756/757/758/759/760/761/762/763/764/765/766/767/768/769/770/771/772/773/774/775/776/777/778/779/780/781/782/783/784/785/786/787/788/789/790/791/792/793/794/795/796/797/798/799/800/801/802/803/804/805/806/807/808/809/810/811/812/813/814/815/816/817/818/819/820/821/822/823/824/825/826/827/828/829/830/831/832/833/834/835/836/837/838/839/840/841/842/843/844/845/846/847/848/849/850/851/852/853/854/855/856/857/858/859/860/861/862/863/864/865/866/867/868/869/870/871/872/873/874/875/876/877/878/879/880/881/882/883/884/885/886/887/888/889/890/891/892/893/894/895/896/897/898/899/900/901/902/903/904/905/906/907/908/909/910/911/912/913/914/915/916/917/918/919/920/921/922/923/924/925/926/927/928/929/930/931/932/933/934/935/936/937/938/939/940/941/942/943/944/945/946/947/948/949/950/951/952/953/954/955/956/957/958/959/960/961/962/963/964/965/966/967/968/969/970/971/972/973/974/975/976/977/978/979/980/981/982/983/984/985/986/987/988/989/990/991/992/993/994/995/996/997/998/999/1000/1001/1002/1003/1004/1005/1006/1007/1008/1009/1010/1011/1012/1013/101 | | |

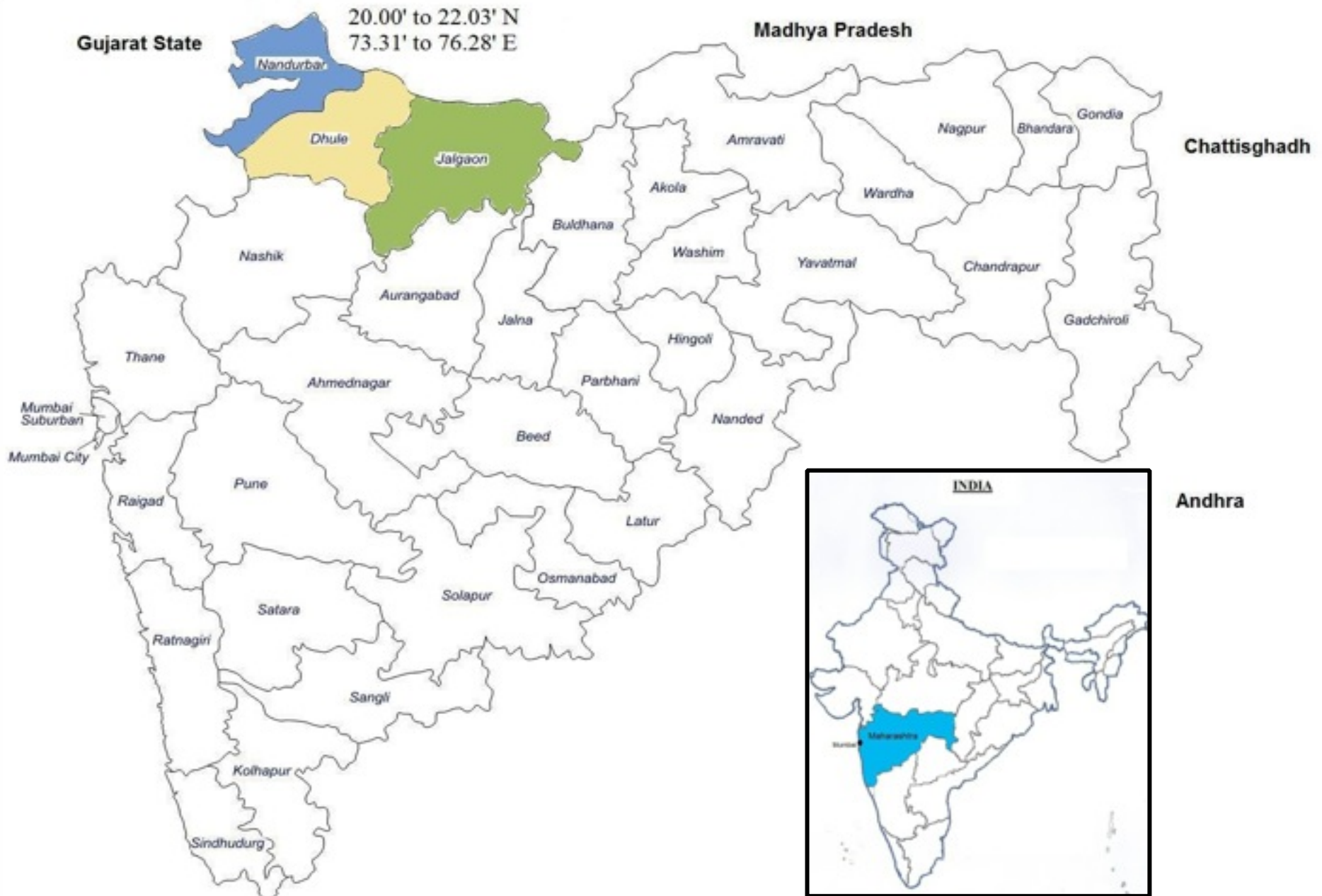
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CONFIRMATION PARENT STUDIES

(MUST)



Map of Maharashtra

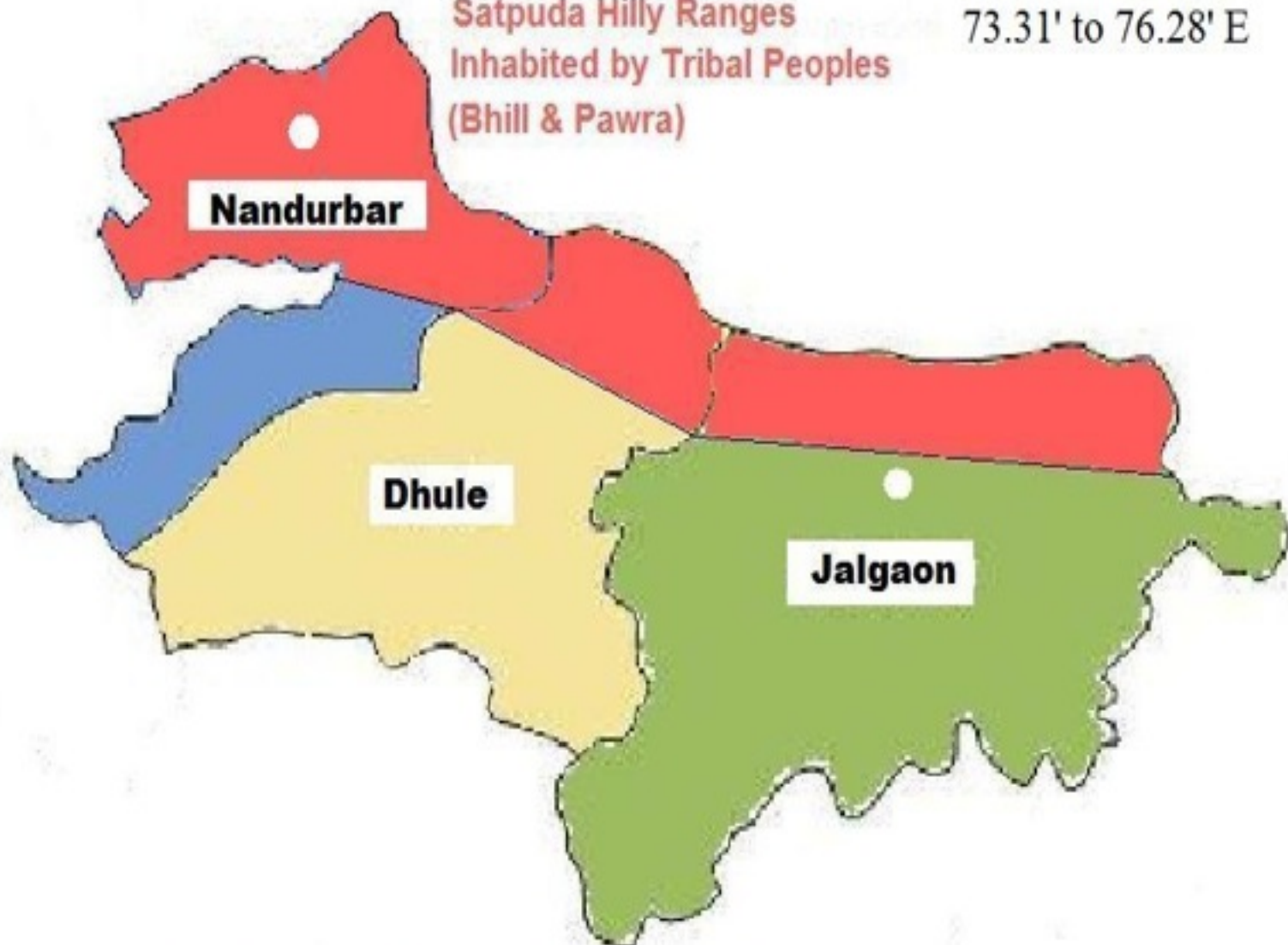


Satpuda Hilly ranges:-
North Maharashtra
Tribes:- Bhil and Pawara



20.00' to 22.03' N
73.31' to 76.28' E

Satpuda Hilly Ranges
Inhabited by Tribal Peoples
(Bhill & Pawra)



3 districts of Maharashtra - Nandurbar, Dhule & Jalgaon



Total Tribal Population of North Maharashtra (Khandesh)
Major Tribal Groups - Two (Bhill & Pawra)

(Fig. in Lakhs)

Dist	Total Population	Tribal Population	Tribal %
<i>Nandurbar</i>	16.48	11.42	69.28 %
<i>Dhule</i>	20.51	6.47	31.56 %
<i>Jalgaon</i>	42.30	6.05	14.29 %
<i>Total</i>	79.29	23.94	---

Population Genetic survey for sickle cell gene

Total population screened in 3 districts	Normal individuals (A+A)	Carrier individuals (A+S)	Sufferer individuals (S+S)
2,05,148	162046 (78.99 %)	40619 (19.80 %)	2483 (1.21 %)



Community Control Center

Sickle Cell Dawakhana

Roshmal Bk.

Tal. Dhadgaon,

**Dist. Nandurbar,
Maharashtra, India**

Centre established

1998

**Maharashtra Arogya
Mandal, Pune**

Location:

**between 3rd & 4th ranges of
Satpuda
21.5' N, 74' E**



Community Control Satellite Centre

Dr. Dada Gujar Sickle Cell Centre

Aakulkhede Bk.

Tal. Chopda

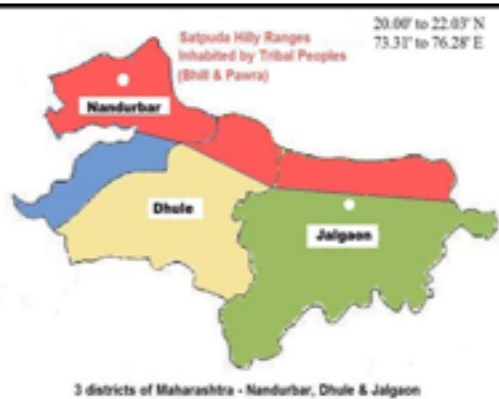
**Dist. Jalgaon, Maharashtra,
India**

**Centre established
2016**

**Maharashtra Arogya Mandal,
Pune**

Location:

21.2472° N, 75.3031° E



Activities of centre

- Diagnosis (blood testing)
- Clinical Examination & ayu. treatment
- Counselling (patients & parents)
- Population genetic survey
- Family studies
- Improvement in QOL
- Marriage counselling
- Genetic counselling
- Training (other NGO)
- Research




Patient's DIARY

- Full Name
- Address
- Age
- Sex
- Caste
- Tribes / Sub Types
- Contact information
- Registration Number along with Date.
- Information about Medicine Doses & Clinical findings.

संदर्भ क्रमांक

नांव _____
 (आइएचएम)

आम्ही



शिकल सेल रुग्णांची काळजी घेते
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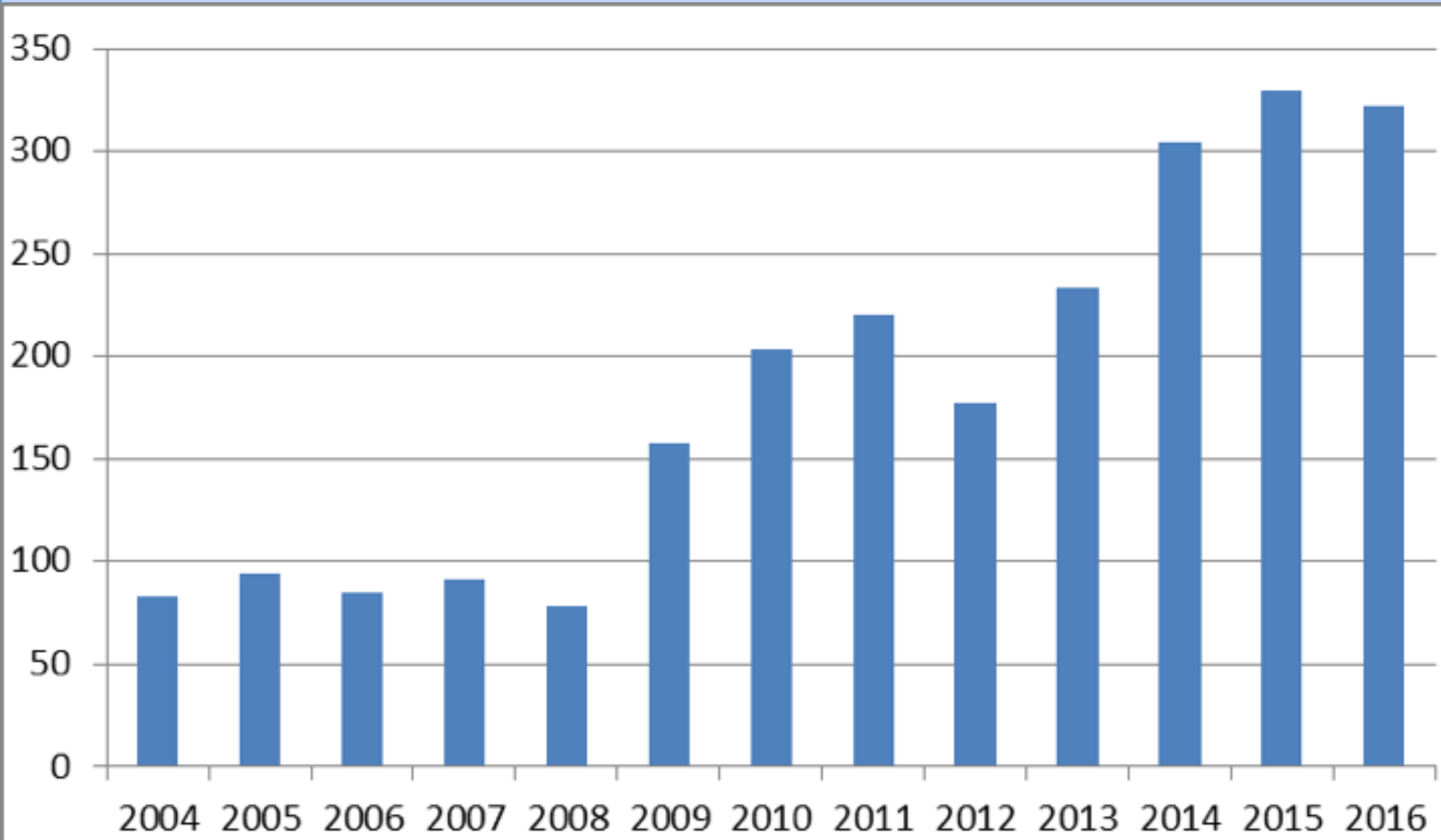
- : अधिक माहितीसाठी संपर्क :-

शिकल सेल दवाखाना
रोषमाळ बु.
ता. धडगाव जि. नंदुरबार (महाराष्ट्र)

महाराष्ट्र आरोग्य मंडळ, माळवाडी, हडपसर, पुणे - ४११०२८
फोन नं. ०२० - २६९९९४०५. फॅक्स : २६९९९९०२
E-mail :-secretary@mam.org.in

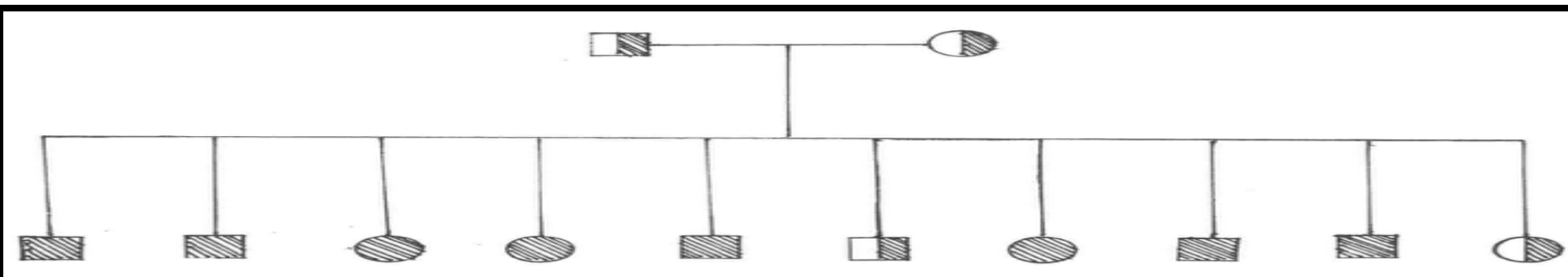
डॉ. सु. ल. काटे ९८५०६५६३२९ डॉ. प्रशांत दळवी ९८२२७८३६३६
डॉ. गिरीश कुलकर्णी ९०९९०९२५४४, डॉ. योगेश प्रभुणे ९४२२४२३४७७
डॉ. राजेंद्र पाटील ९४२०२५६९७९

SICKLE CELL PATIENTS IDENTIFIED FROM LAST 12 YEARS (NANDURBAR, DHULE, JALGAON, MADHYA PRADESH AND GUJARATH)



We have registered **>3261* homozygous patients from this area**

Family of 8 sickle cell anaemia patients



OBSERVATIONS

- GENERAL CONDITION OF PATIENTS - IMPROVED
- IMPROVEMENT IN ANAEMIA STATUS
- CRISIS - SEVERITY AND DURATION DECREASES
- NO ALLERGIC REACTION

ALLOPATHIC DRUGS

- Hydroxyurea - to reduce severity of symptoms -
but
 1. Not affordable
 2. Life long treatment
 3. Repeated hematological investigations needed

MODERN TREATMENT

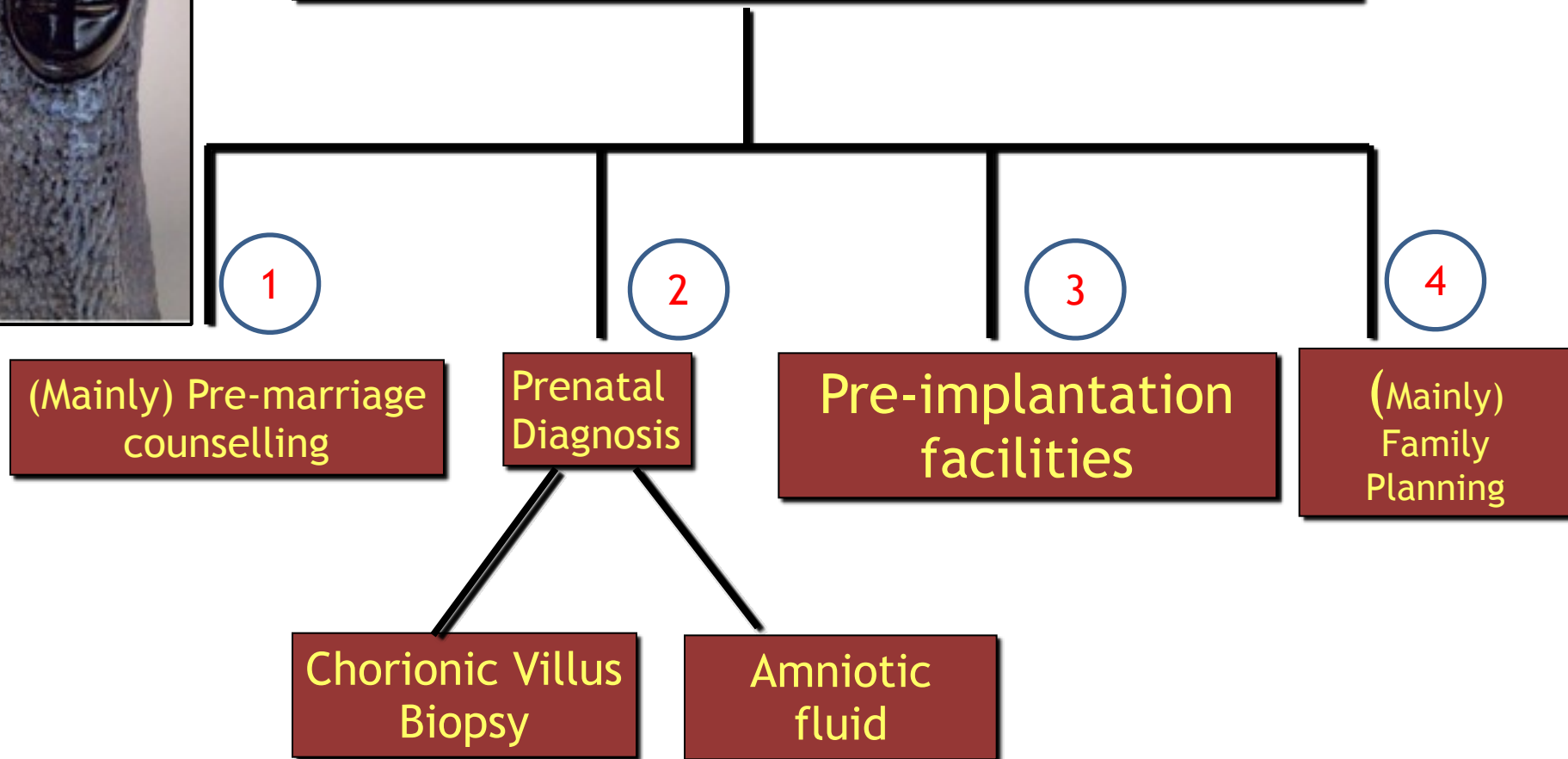
- Disease is not curable by medicine or surgery
- B.M.T.
- Stem Cell Therapy
- Gene therapy

(available but costly)

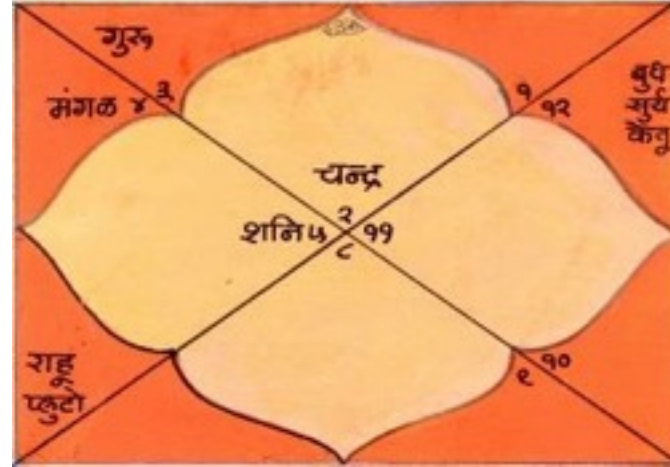


Prevention strategy

Aim - Avoid birth of S.C.D. child



Counselling - Information, Education and Communication Approach



विवाह जुळविण्या नाही जरूरी
पाहणे राहु, केतू, मंगल
रक्त चाचणीनेच टक्केल
सारे असंगल.

Community Control Programme Centre is really dedicated centre

- ✓ Land donated by tribal youth (Manoj Pawra)
- ✓ All administrative & Laboratory diagnosis work (local tribal youth)
- ✓ Located at Geographical difficult Satpudha Hill Ranges, according to need of tribals
- ✓ Diagnosis, treatment and counselling free of charge
- ✓ All volunteers work sincerely without any expectations
- ✓ Patients, parents and people are Happy with our friendly treatment

Hence it is Dedicated Centre

- **ACCURATE DIAGNOSIS**
- **PROPER MEDICAL CARE**
- **GOOD NUTRITIONAL SUPPORT**
- **GOOD FAMILY SUPPORT**

**CAN
ALLEVIATE SYMPTOMS**

Prolong life help Sickle cell patient to be active & happy

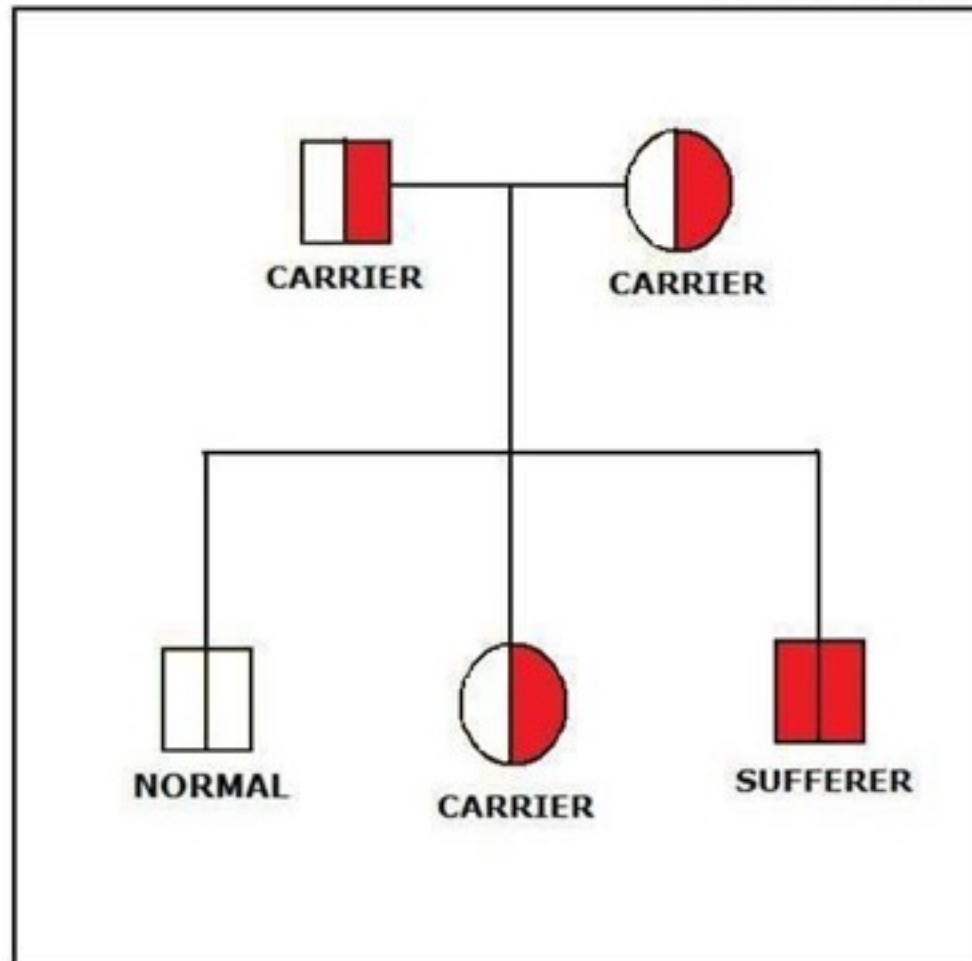


Ayurvedic perspective

Ayurvedic treatment Prior to conception

सुप्रजा निर्मिती

RESEARCH ...



Some memory of our 100 th CAMP



Team of our 100 th CAMP



Patient's at Sickle Cell Dawakhana



Our felt sorrowful As we lost our supporter



हर खुशी हर तमन्नासे दूर हूँ
जी रहि हूँ इस लिये की मजबूर हूँ



**_^_ WE OWE TO _^_
DR. DADA GUJAR &
DR. GRAHAM SARGENT**

THANK YOU....

Let us unite together and combat this
genetic disorder

Sickle Cell Team
Sickle Cell Department
Maharashtra Arogya Mandal
Hadapsar, Pune-28

**[www.sicklecell-
mam.org](http://www.sicklecell-mam.org)**

THANK YOU....

Let us unite together and combat this genetic disorder

Sickle Cell Team
Sickle Cell Department
Maharashtra Arogya Mandal
Hadapsar, Pune-28

www.sicklecell-mam.org