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# Patient Case Studies

*Doctor, you have given me my life back*

Dr Joseph Chandy (Kayalackakom)  
[www.b12d.org](http://www.b12d.org)

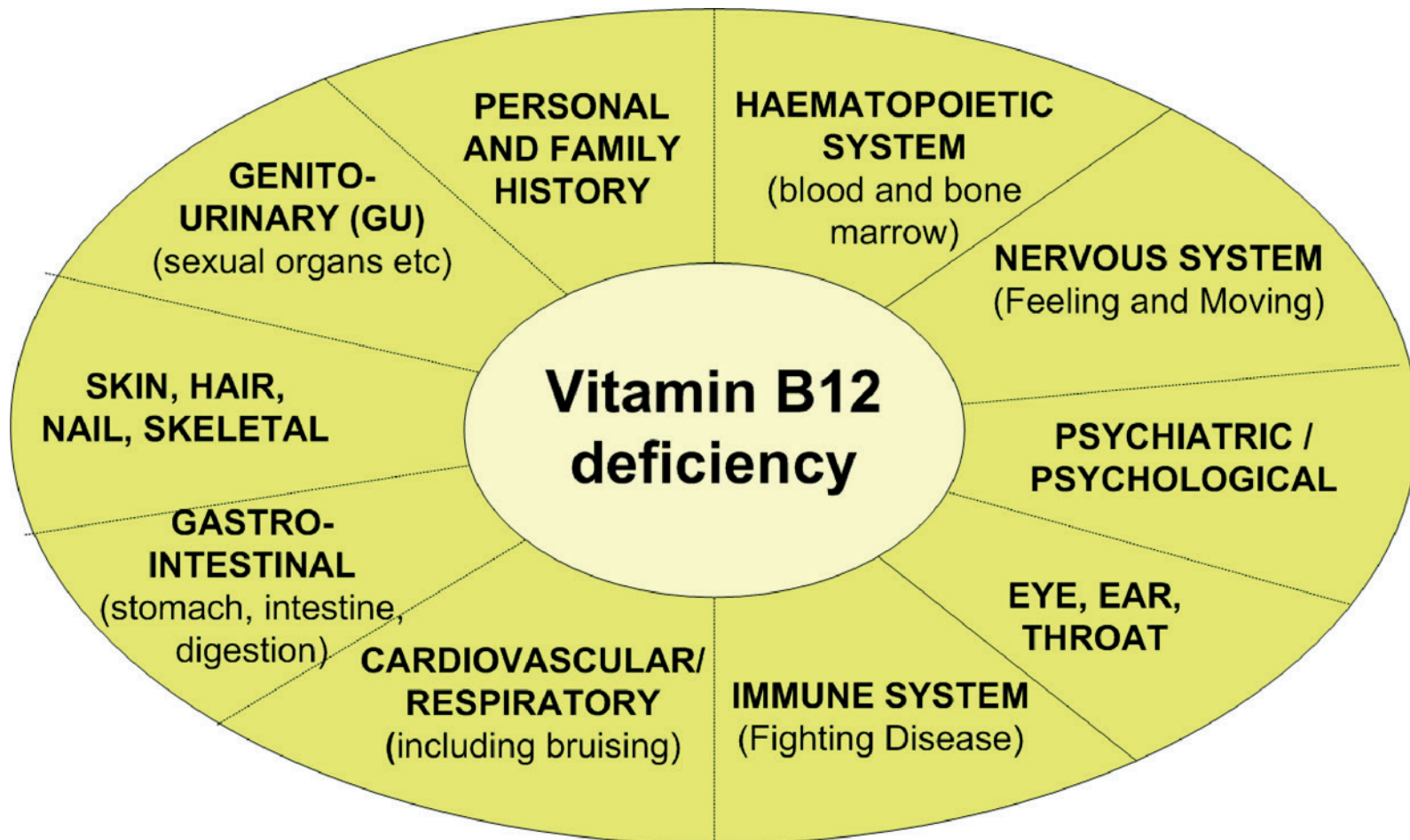
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# Three periods in the history of

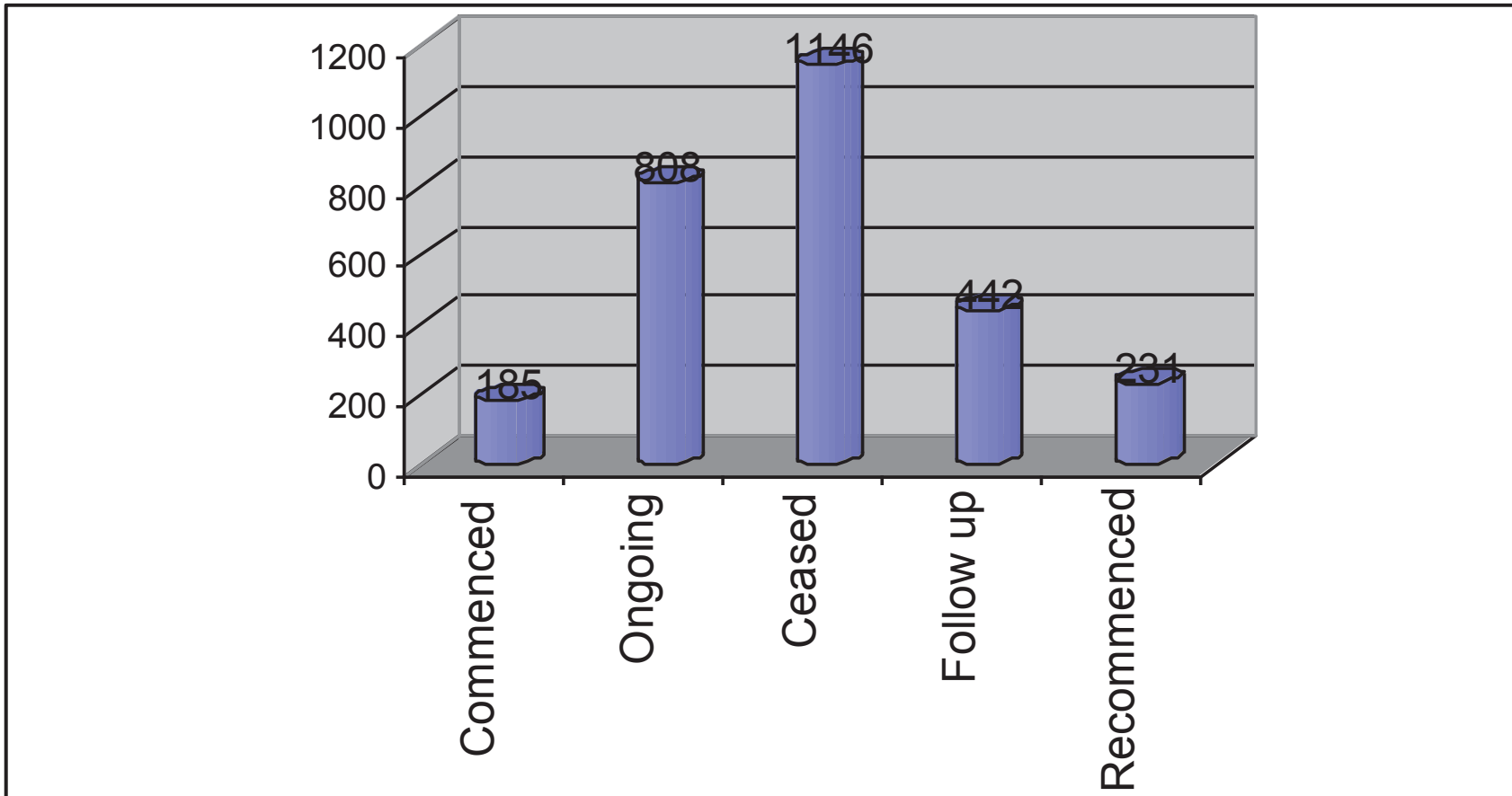
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- I 1824-1926 – described an untreatable wasting disease which took many forms (Combe 1824, Addison 1855, Biermer 1872, Ehrlich 1880 (de-re-generation, BL cells, megaloblastosis), Russell 1900 (SACD))
- II 1926-1979 – the Liver diet (Minolt & Murphy), discovering B12 and the mechanism
  - deprivation, poverty, poor diet, malnutrition not only in 3rd world countries, through 2 world wars 1914-1919, 1939-1945
  - Since 1960s sustained improvements in standards of living which altered the blood clinical & physiological picture
- III 1979-today – widespread refusal to accept the condition exists

# A multi-system, poly-glandular, multipoint disorder



# Blood B12 level drops rapidly following withdrawal of treatment (matches symptoms relapsing)





# Exclusion Criteria

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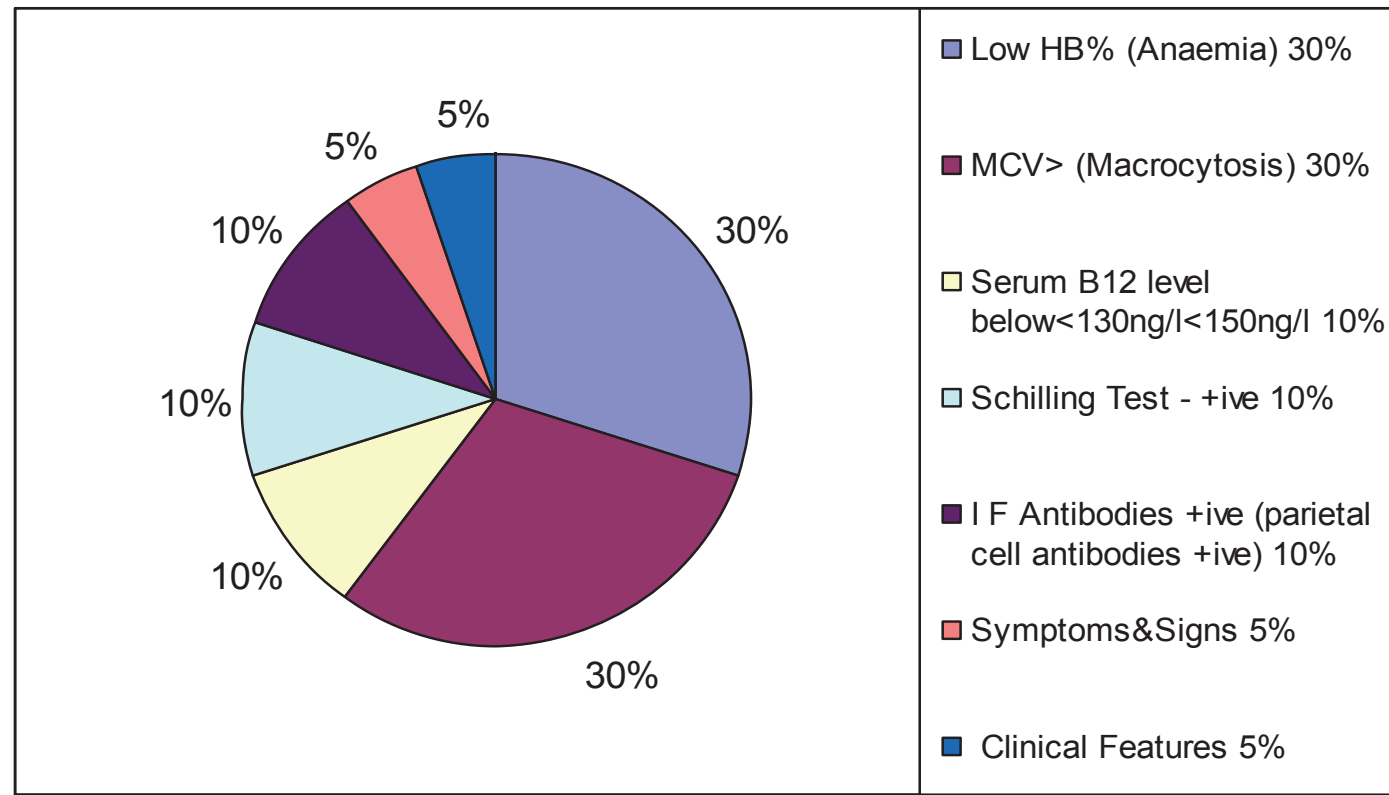
- Depressive illness
- Phobic anxiety state
- Neurosis
- Bulimia
- Anorexic nervosa
- Vasovagal attacks
- Partial seizure
- Epileptic seizure
- Brain tumour
- Cranio pharyngeoma
- Temporal arteritis
- Gastric colon and renal cancers
- Cerebral aneurism

## **The Chandy Diagnostic Criteria for diagnosing B12 deficiency**

Compared with the Addisonian criteria for diagnosing Pernicious Anaemia – many tests required for an Addisonian diagnosis are no longer available

# B12 deficiency – synonymous with Pernicious Anaemia

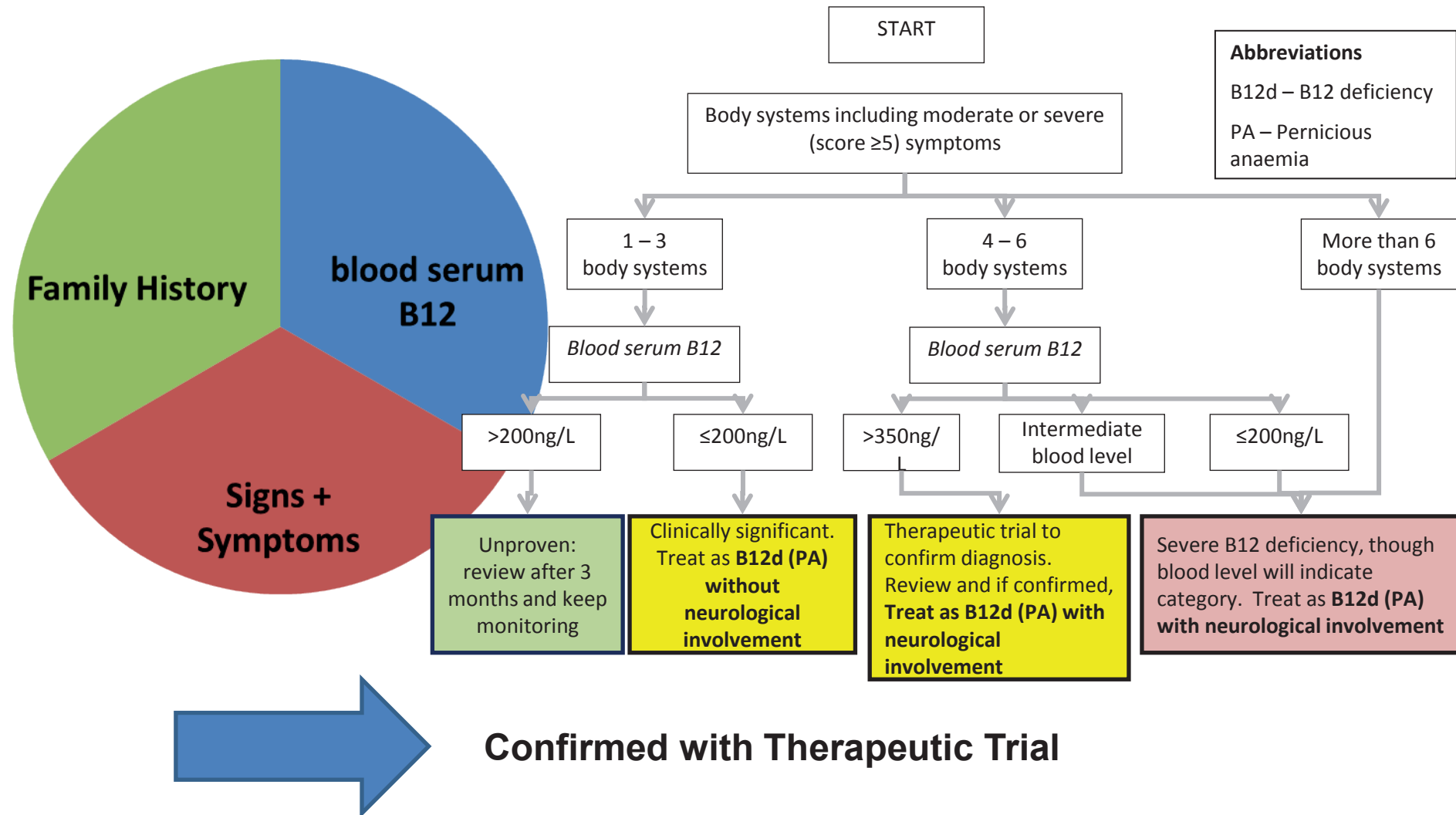
## “Addisonian Criteria” or the Complicated Way



**Optional additional tests (expensive, difficult, unreliable)**

Schilling Test (\* radioactive materials)  
 Estimation of Urinary Methyl Malonic Acid  
 Plasma Homocystine  
 Transcobalamin II Estimation  
 Bone Marrow Examination

# B12 Deficiency – clear decision tree for diagnosis and treatment “The Chandy Diagnostic Criteria”



## **Energy / Haemopoetic System Case Studies**

Extreme fatigue, ME/CFS, fibromyalgia. Often combined with endocrine system malfunction for example hypoadrenalism, hypothyroidism see section on Autoimmune conditions pg 29

## B12 deficiency without macrocytosis but with neuropsychiatric symptoms

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Both mother and daughter presented with similar neuropsychiatric symptoms, along with recurrent anaemia, extreme fatigue, low mood, breathlessness and weakness. These patients are especially important to Dr Chandy – he delivered the daughter in November 1970, 15 days after taking over the practice.

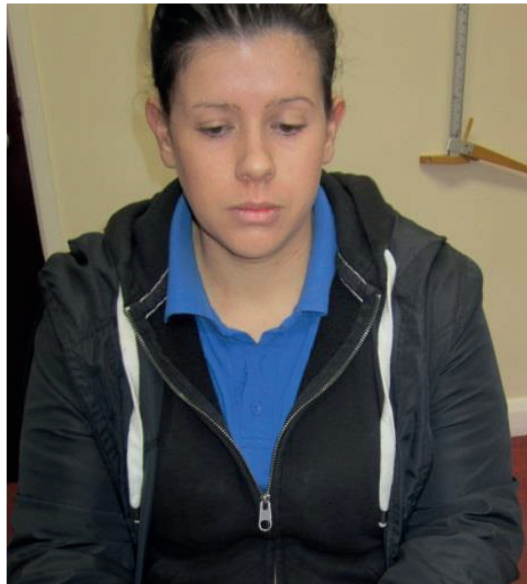
The Mother presented with recurrent anaemia and neuropsychiatric symptoms which didn't respond to iron supplement. After 10 years (1981), Dr Chandy diagnosed B12 deficiency (mother's blood level 185ng/L) and instituted B12 replacement therapy by injection.

In 1997 the daughter attended with blood B12 level 137ng/L and also recovered with B12 replacement therapy.



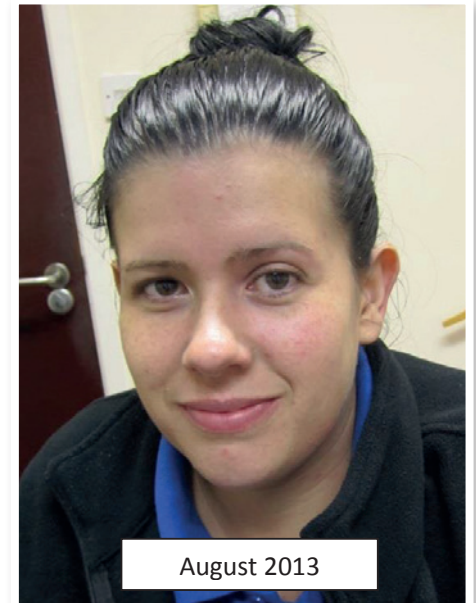
# B12 deficiency and hypoadrenalism

**B<sub>12</sub>**  
DEFICIENCY



May 2013

This lady was diagnosed with B12 deficiency in another practice in Feb 2011 with blood B12 176ng/L, and started on three monthly injections. These did not resolve the problem – by Nov 2011 her blood B12 was 132ng/L and she suffered fatigue, lack of energy, joint pains. On joining Dr Chandy's practice she commenced daily B12 injections which resolved most of the problems, but in May 2013 low early morning cortisol was detected and physiological replacement dose was provided. The results can be seen within 3 months, on the right.



August 2013



## Child withdrawn and lacking energy – mother diagnosed at same time

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Child was lacking energy, becoming withdrawn and not going out to play; on testing he had low levels of serum B12 (133ng/L (normal range 350-900), folic acid (4.9mg/L (5-20)) and ferritin (18mg/L (25-280)). Treatment for deficiency in all three resulted in the happy child observed.

Suspecting a genetic link, the mother was tested: B12 112; folic acid 3.7, ferritin 25. The mother is also much better now she is receiving treatment. She had previously thought tiredness was due to having young son.





## Neurological Case Studies

Numbness, Pins & Needles, phantom pains

Loss of power especially one limb, Sub-Acute Combined  
Degeneration (SACD)

## Single limb paralysis

- Female, age at diagnosis 17
- 27/01/2004 Passing out without warning, 4 fainting attacks in one year. Pale yellow complexion, Pins & needles in fingers, hair loss, depression, Left leg below knee paralysis.
- Maternal uncle B12 deficient (B12 120ng/L)

	Jan '04	Jul '04	Aug '06
B12 level	247	1522	1349
Folate	3		
TSH	2.42	1.24	2.17
Haemoglobin	13.3	12.9	11.5
MCV	90.1	87.8	78.3

Has stopped treatment twice since starting:

1 – weak legs

2 – severe neuropathic pain in back



# Mother champions the cause for her daughters



Mother was recorded with a B12 level in Dec 2005 of 211ng/L, and commenced on OC (oral) B12 tablets.

One daughter was diagnosed with Multiple Sclerosis (MS) by a neurologist, and since June 2006 she has been treated with immune-suppressants. Her general condition and left sided weakness worsened.

Now this daughter is on B12 replacement therapy and improving, and all of the symptoms of the other daughters are also improving with B12 replacement therapy.

The response to treatment confirms the B12d diagnosis.

**Daughter's blood serum B12**

Jun 2006	Jul 2010	May 2011	May 2013
268	157	544	375

# Left Oculomotor nerve paralysis

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- B12 level was 252ng/L in May 2009
- 9 days in specialist hospital – no diagnosis no treatment (eye patch and sent home)
- Had double-vision, ptosis left eye, orbital headache (same eye). The photo is from her video interview last year
- Injections of B12 every 2 months was not adequate, but injections every month her sight now fully restored and she works in SpecSavers



# Lhermitte's Sign – shooting pain



This lady was so delighted with the result that she asked to be photographed posing in her previous twisted posture (left) to show the change.

She presented with MS-like symptoms and muscle spasm due to Lhermitte's Sign causing her to lean to the right, also unable to sleep for pain.

In July 2013 her B12 was 194ng/L (normal range 350-900) so injections were commenced. Improvement was obvious within 8 weeks.

B12 deficiency is usually genetic so her father was tested – he was diagnosed and treated and “cannot believe the difference”





# Motor Nerve Damage



This lady used to run a creative media company. Then for 10 years she had no strength in her writing hand (left) which limited her ability to work, and had 2 children taken into care and another born disabled. In Feb 2009 her blood serum B12 was 172ng/L.



Once treatment was started she required 33 loading doses (1mg B12 injections given 2 days apart), followed by injections every 2 months until an analysis of her symptoms has revised this (the revision was made at the same time as the photo on the left was taken) – she now gets an injection every week.



She is now able to write and has returned to work full time.

# Facial weakness/ Palsy



This lady was suffering from falls, with paralysis on her right side, and weighed 5st in 2000. Her B12 levels deteriorated from 268ng/L in 2000 (when she started on oral B12 treatment because the GP practice was not allowed to treat with injections) to 237 in 2006, to 148 in 2009, at which time she was referred to a neurologist with MS-like presentation who gave no diagnosis nor treatment proposal.

Following intensive B12 replacement therapy she has gained weight from 5st to 8st, her facial palsy and paralysis are totally reversed. We believe that we should have been allowed to start treatment when she presented with neuropsychiatric symptoms in 2000, and would have avoided 10 years of suffering, and the loss of her job.

Recently both son and daughter (the daughter is photographed on the right) were diagnosed with B12 deficiency – they are now receiving treatment.



# MS-like presentation

Female born 1972 – history Mother B12 deficiency, maternal aunt B12 deficiency and MS 1995 depression. Under the care of Community Psychiatric Nurse (CPN), and 1996 menorrhagia and dysmenorrhoea 1997 (aged 25) presented with pins & needles in hands and feet, unsteady, dizziness, depression, tired and sleepy, heavy periods and pain. Referred to Neurologist: - “mildly disarthric, angle clonus, bilateral finger nose and heel shin ataxia, impaired sensation to pain below Rt knee ... ?demyelinating. MRI – brain plaques of demyelination. Cervical cord signal abnormality is consistent with demyelination. CSF – oligoclonal bands in CSF and not in serum.”



B12 level 189ng/L. Treatment commenced in April. 1997 September (5 months later) Neurologist:- “she has improved considerably since I last saw her in May. There is mild limb ataxia burning in the lower limbs”. PCT decides to discontinue the B12 treatment early 2002.

Late 2002 presents with depression, anxiety, using wheelchair more, registered blind, optic atrophy, incontinence of urine, painful Rt foot. Blood serum B12 340, dropping to 158 in August 2003. Treatment restarted August 2003

2006 both patient and husband delighted with her improvement in mental and physical state. Managing to get through most household chores and not wheelchair dependent anymore, blood serum B12 819ng/L



## Bell's Palsy affecting left side of face

This is a case of Bells Palsy. The condition is visible over left eye and also causing pain in the left ear in the photograph on the left below (taken 2 Aug). The standard treatment is large doses of oral steroids.

We ordered her B12 level at the same consultation and completed the signs and symptoms sheet which confirmed that she could be B12 deficient. Her B12 level came back as 345 (2 Aug 2011)

With that provisional diagnosis in mind, a therapeutic trial was started. The effect can be seen within 3 ½ weeks (photo on right - 26 Aug 2011). The Bells Palsy responded to B12 treatment without giving large doses of steroids (which of course is harmful). Her blood level was “low normal” and the treatment protocol states that therapeutic trials can be commenced at this level



# Ramsay-Hunt syndrome

For the last 10 years this lady has had epilepsy and anti-epileptic medication for seizures. In March 2006 she had a B12 test which gave a level of 182ng/L, but her then doctor didn't recognise this.

With injections of B12 every 2 months (the current standard treatment for Pernicious anaemia with neuropsychiatric symptoms), she still suffered from fits, but when the treatment was given every month her fits stopped and she has reduced her anti-epileptic medication considerably.

She recently (2011) developed left side facial palsy (Ramsay-Hunt syndrome – facial palsy and severe pain), neuropathy in the left arm, herpes zoster lesions on outer ear and neck. The hospital diagnosed migrainous neuralgia (April 2011). The practice revised injections to alternate days and then weekly, which reversed the symptoms.



# Psychiatric Symptoms Case Studies

## Totally drained, depressed, skin rash all over his body

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Following a long period of depression, psychosis, hallucinations, fatigue due to lack of sleep, severe dermatitis this man was about to lose his wife and his job.

He came to the surgery to find out his blood serum B12 was 145ng/L (Jan 2011). His mother is B12 deficient and receiving B12 replacement therapy.

He started on treatment and he can't believe the difference.





# ME, Depression, Fibromyalgia, Munchausen's by proxy, joint pain

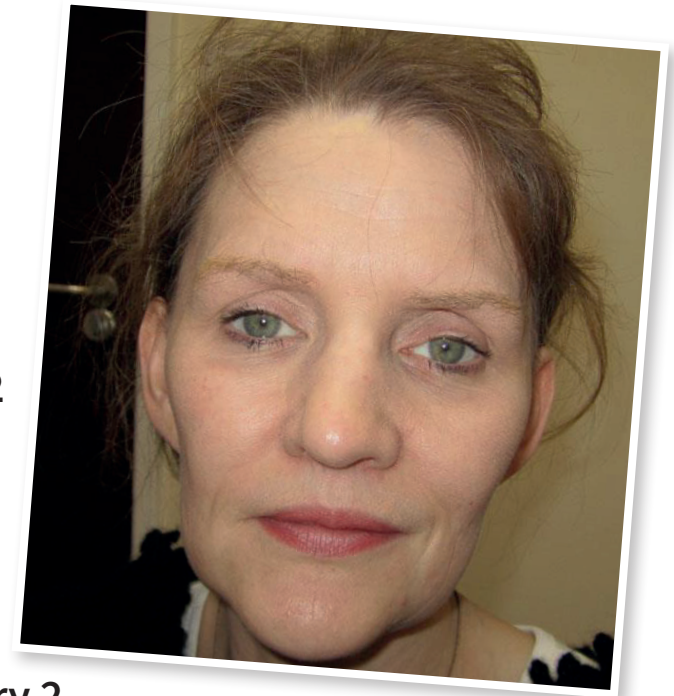
**B<sub>12</sub>**  
DEFICIENCY



This lady (see also previous case study in fatigue) used to run a creative media company. Then for 10 years she had no strength in her writing hand (left) which limited her ability to work, and had 2 children taken into care and another born disabled. In Feb 2009 her blood serum B12 was 172ng/L.



Once treatment was started she required 33 loading doses (1mg B12 injections given 2 days apart), followed by injections every 2 months until an analysis of her symptoms has revised this (the revision was made at the same time as the photo on the left was taken) – she now gets an injection every week.



## **Eye, Ear, Throat Case Studies**

Glossopharyngeal nerve pathology leading to difficulty swallowing, persistent cough. Etc.

# Glossopharyngiditis (difficulty swallowing)

July 2004 this lady's blood serum B12 was 224ng/L (illustrated below) and she suffered from difficulty swallowing. If she had been treated then, the demyelination of the nerve could have been prevented.



She was referred back and forth to various specialties to find the cause of her swallowing difficulties, loss of weight, fatigue and depression. She accidentally came to Dr Chandy in Nov 2006. He diagnosed B12 deficiency although B12 blood level recorded as 446ng/L. He commenced her on an intensive course of B12 replacement therapy and soon she was able to join her husband and children for tea.



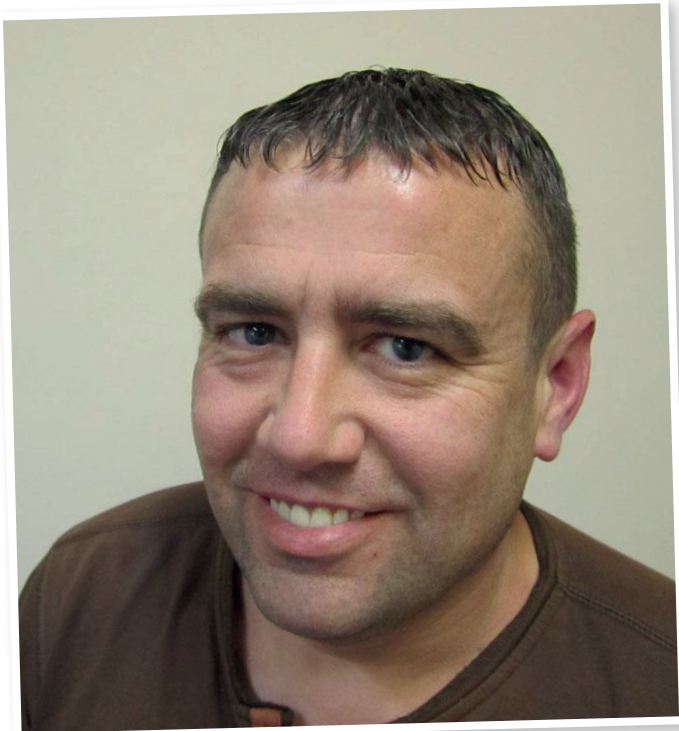
## Persistent cough and swallowing difficulty, lasting 1 year

This man had been a delivery driver, but was unable to sleep because of his cough, so he couldn't stay awake at the wheel.

His B12 level in March 2010 was 164ng/L. He's now receiving 1mg B12 each month by injection, and it has restored his nerve function which means he no longer has either the cough or the swallowing difficulty.

By March 2011 he was back to his previous job.

His son (now 18) suffered 3 years of coughing and choking on food, and it was only when the father was diagnosed and treated that the son came forward, was diagnosed, and commenced treatment. The recovery was miraculous!





# Immune system and Autoimmune Conditions

## Case Studies

B12 deficiency not only affects the red blood cells,  
it also affects the platelets and white cells,  
including immune system

# Can people die of B12 deficiency?

## Two Case Studies

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### A.C. – born Feb 1977

- Son born Nov 1998
- Nov 2003 – B12 145. 5 inj then oral
- Jan 2004 – B12 234
- Jun 2004 – B12 427
- Nov 2004 – B12 362
- Aug 2005 – B12 396
- Sep 2005 – B12 391. Required 3\* injections Jan 2006
- Aug 2009 – B12 255. Injections IM started
- Sep 2010 – twins (female) born, mother well 7 happy no Post-Natal depression
- IM inj continued throughout pregnancy and continuing

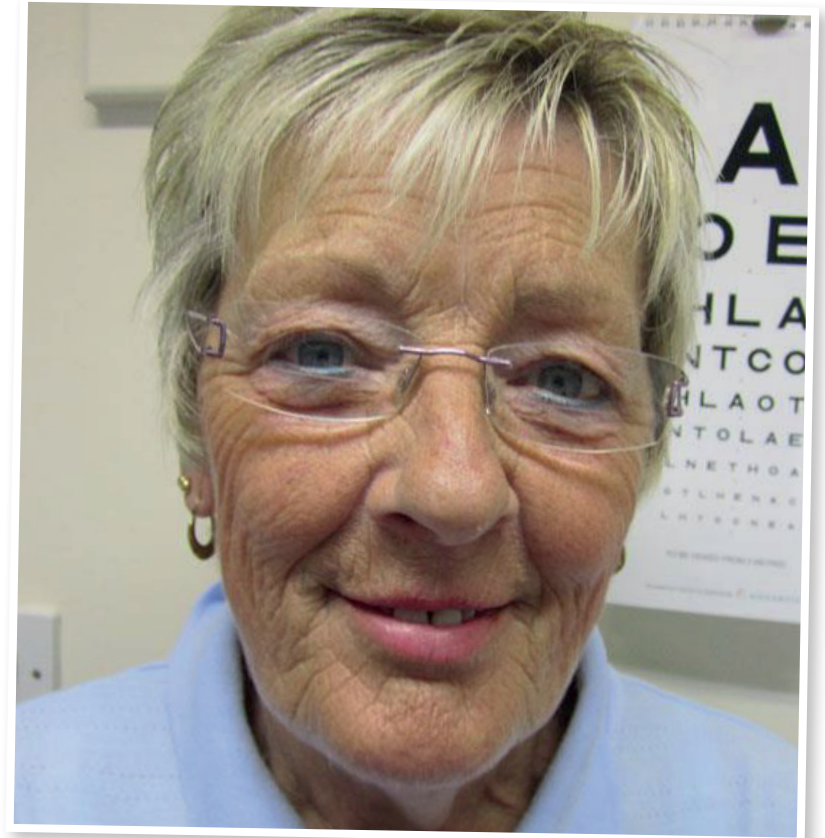
### R.C. – born Nov 1968

- Mar 2005 – B12 177. Inj B12 started
- Aug 2005 – B12 >2000
- Jan 2006 – B12 1815
- 2007 – Protocol prevented injections being given, & pt confused so injections not restarted in 2009 when ban was lifted
- Apr 2010 – Pt contracts influenza & bronchial pneumonia – consolidation in both lungs
- Admitted to hospital
- Date of death (aged 41) May 2010 leaving husband & daughter

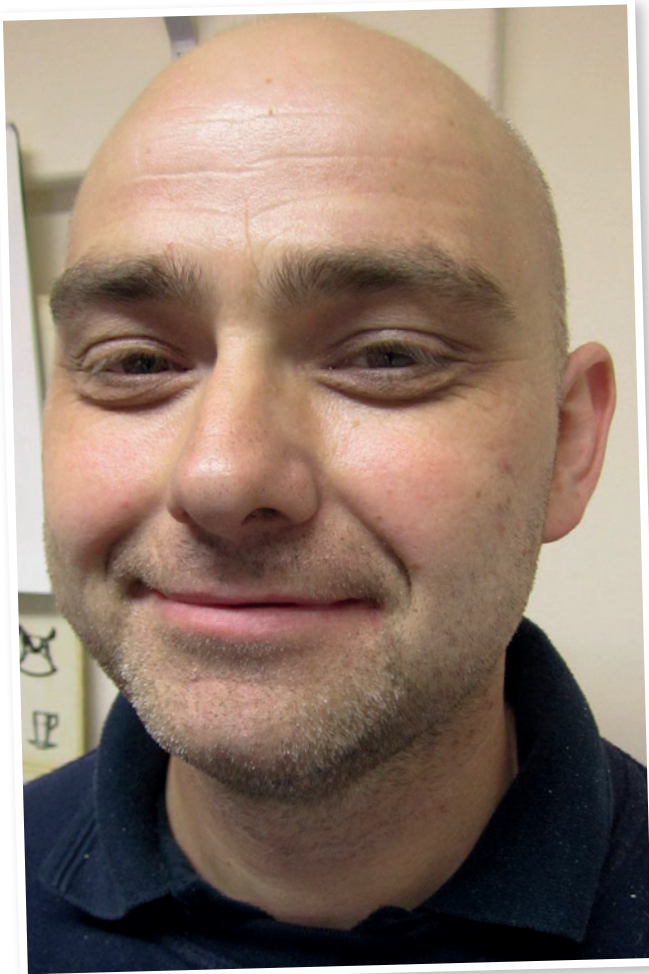
## B12 and Adrenal insufficiency

In April 2005, this lady had a B12 of 179ng/L although no action was taken by her doctor. By July 2009 her early morning cortisol was 138, falling to 96 in Nov 2009.

Following B12 replacement therapy, her adrenal insufficiency was completely reversed and her general physical health has dramatically improved.



# Common Immunodeficiency



Recurrent chest infections & bronchiectasis. Hospital diagnosed immunodeficiency and started immunoglobulin treatment from 2007. In May 2013 found to have low B12 140ng/L (normal range 350-900) and treatment started.

By early June (immunology clinic) he reports that he has been very well, suffers no recent infections, no diarrhoea, no proteinuria. Vitamin D supplementation is still required.

## **Cardiovascular / Respiratory System Case Studies**

Palpitations, chest pain, heart-disease-like presentation

Breathlessness and asthma-like presentation

# Cardiomyopathy and mitral-aortic defect in pregnant mother

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Woman (32 yo Feb 2011) arrived with cardiomyopathy / mitral-aortic regurgitation and closure of the ventricular tunnel, concerned about getting pregnant because of her own frailty and likely heart defects in baby.

Blood serum B12 was found to be 283ng/L (normal range 350-900) and replacement therapy commenced. Mother rapidly gained strength, and when she wanted a baby, folic acid supplements were added. Hospital cardiology clinics were surprised that she had a healthy pregnancy and no post-natal problems, and baby born July 2013 healthy and with no heart defect.



## Vasculitis due to B12 deficiency / hypoadrenalism



28 years old, profession nurse, already diagnosed B12 deficient (248ng/L 2012) but not compliant with treatment. Attended surgery August 2013 as shown in photo.

Initially suspected allergic reaction but cortisol level was 130nmol/L (normal range 500-700 in morning) and B12 243ng/L (normal range 350-900), which in conjunction with extreme fatigue and breathlessness confirmed vasculitis rather than urticaria.

Emergency treatment was given before cortisol results were known, proven to be correct treatment.

Patient now compliant with B12 replacement therapy (injections alternate days), along with oral hydrocortisone

# Erupto-Xanthoma

We know that B12 is important for lipid metabolism, and this gentleman arrived with skin bumps and gout (2003 – uric acid 0.51, triglyceride 15.59mmol/L, cholesterol 17.5mmol/L). His B12 level was 172 at this time. This substantially raised his risk of CVD.



We have also observed a fascinating phenomenon – as well as genes for B12 being passed in families, people with B12 deficiency tend to select other sufferers as partners (this man is pictured with his wife (see case study on page 20), who presented with MS-like symptoms and is benefiting from treatment).

The gentleman was seen by a chemical pathologist and dermatologist. They offered treatment but it had no impact until B12 replacement therapy was also commenced.



# Gastro-Intestinal tract Case Studies

Colitis, IBS, Mouth Ulcers

## Swallowing difficulty, extremely incoherent speech and colitis

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(Male aged 74) This combination of symptoms led us to suspect B12 deficiency, and tests indicated B12 level of 155ng/L.

After 6 months of treatment (loading dose followed by injections monthly) his wife and neighbours cannot believe the transformation! He himself reports that his throat feels clear, he no longer chokes on fish nor has swallowing difficulties, and his speech is clear.

As an added bonus, his hair is growing back. Unfortunately the colitis has not yet improved; in many patients the colitis is one of the first symptoms to improve.



# Skin, hair, connective tissue, joints Case Studies

# Subtle Cobalamin deficiency with clinically deficient presentation ME, Fibromyalgia, myositis

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Christmas 2006



May 2011

# Subtle Cobalamin deficiency with clinically deficient presentation ME, Fibromyalgia, myositis

- Female born 1948
- 16/11/2006 extreme fatigue, sleepy all day, dizziness, falls, blurred vision, low mood, suicidal, depression, weepy, agitation, tingling in hands & feet, unexplained hair loss, headache, loss of libido, neuropathic pain (painful hips), spasm of lower limb
- Had been diagnosed Myositis, ME, Chronic Fatigue Syndrome, MS, osteoarthritis in different hospitals
- Referred to orthopaedic surgeon for hip pain

	Nov '05	Mar '06	Aug '06	Nov '06	Jan '07	May '07	Mar '08	Jul '08
B12 level	524	418		707	520	2000		383
Folate	7.4	7.2		14.3	10.9	15.6		6.2
TSH	4.4	6.78	2.32		4.13	1/77	7.85	2.32
Haemoglobin	13.9	13.7	13.0	13.9	13.7	13.6	13.5	13.4
MCV	90.9	89.5	89.2	87.1	88.7	90.5	86.6	86.9

- Oral supplements (OC)
- 16/11/06 commenced 3 month therapeutic trial injections
- Dramatic improvement in all areas. Feels like a new person. Walking stick discarded, no longer uses commode



# Rheumatoid Arthritis



“TB” initially presented with many of the signs and symptoms of B12 deficiency 15 years ago – the blood test showed that she had both B12 deficiency and underactive thyroid.

2 years ago, she stopped both of the above treatments herself (non-compliance). Shortly afterwards, she presented with classic rheumatoid arthritis symptoms: swollen painful joints. Shwe didn’t make the connection between stopping the treatment and the pain. Diagnosis of rheumatoid arthritis was made by hospital consultant who commenced her on methotrexate

As she was still in a lot of pain and joint swelling, she presented to her GP (Dr Chandy), who suggested she should go back on Vitamin B12 injections and thyroxine. Within 3 months, she is totally recovered (Aug 30 2011) and she herself stopped the methotrexate which includes powerful pain killing medication

# Alopecia

The BBC documentary (Oct 2006) describes one lady with alopecia. Here we present a man.

His signs and symptoms:

- B12 level in the normal range (591ng/L in March 2011 – whilst taking oral supplements)
- Neuropsychiatric symptoms and extensive alopecia
- Conventional treatment by dermatologist had no impact
- The first photo (below) was from March 2011. The second one is 4 months later (9 July) with intensive B12 treatment, the third 20 August
- And the final one (in blue shirt) 3 Nov 2011



March 2011



9th July 2011



20th August 2011



3rd Nov 2011

# Lupus, Rheumatoid Arthritis & Raynaud's disease

She suffered Joint inflammation, skin lesions, lip and mouth ulcers, and poor circulation (blue fingers); in 2008 her B12 level was 674 and by March 2011 it was 266. She was also taking 2 immunosuppressant medications for her rheumatoid arthritis.

The ulcers, joint inflammation – in fact all of the above symptoms disappear when she receives frequent (weekly) injections and reappear when she misses an injection or two. She no longer takes the immunosuppressant medication (on her own volition).



May 2011, after 4 wks treatment



June, after 2 more weeks'



2 Aug



8 Aug



# Ankylosing spondylitis / sacroiliitis



Under the care of the rheumatologist, the diagnosis of ankylosing spondylitis and sacroiliitis was confirmed by MRI. The gentleman was given pain relief (huge doses of hydrocodein, oramorph, etc) and humira injections every 2 weeks.

He (a former boxer) came to the practice 1st July 2011 with his wife and child complaining of extreme fatigue, peripheral neuritis and other signs and symptoms consistent with B12 deficiency.

Blood B12 level came back at 350ng/L (folic acid 4.6, Haem 13.6, MCV 90), so a diagnosis of subtle B12 deficiency was made. The usual B12 injection replacement programme commenced.

Within days he noticed an “unbelievable improvement” in all areas, including his back and neck (and other joint) pains and inflammation. In particular he could now pick up his baby and play football with his older son. He himself began reducing all of his medications and stopped the delivery of 2 weekly humira injections



# Genito-Urinary System Case Studies

Incontinence, Infertility, Miscarriage



# Fertility and tiredness



An interview of this lady is available on the B12d.org web site.

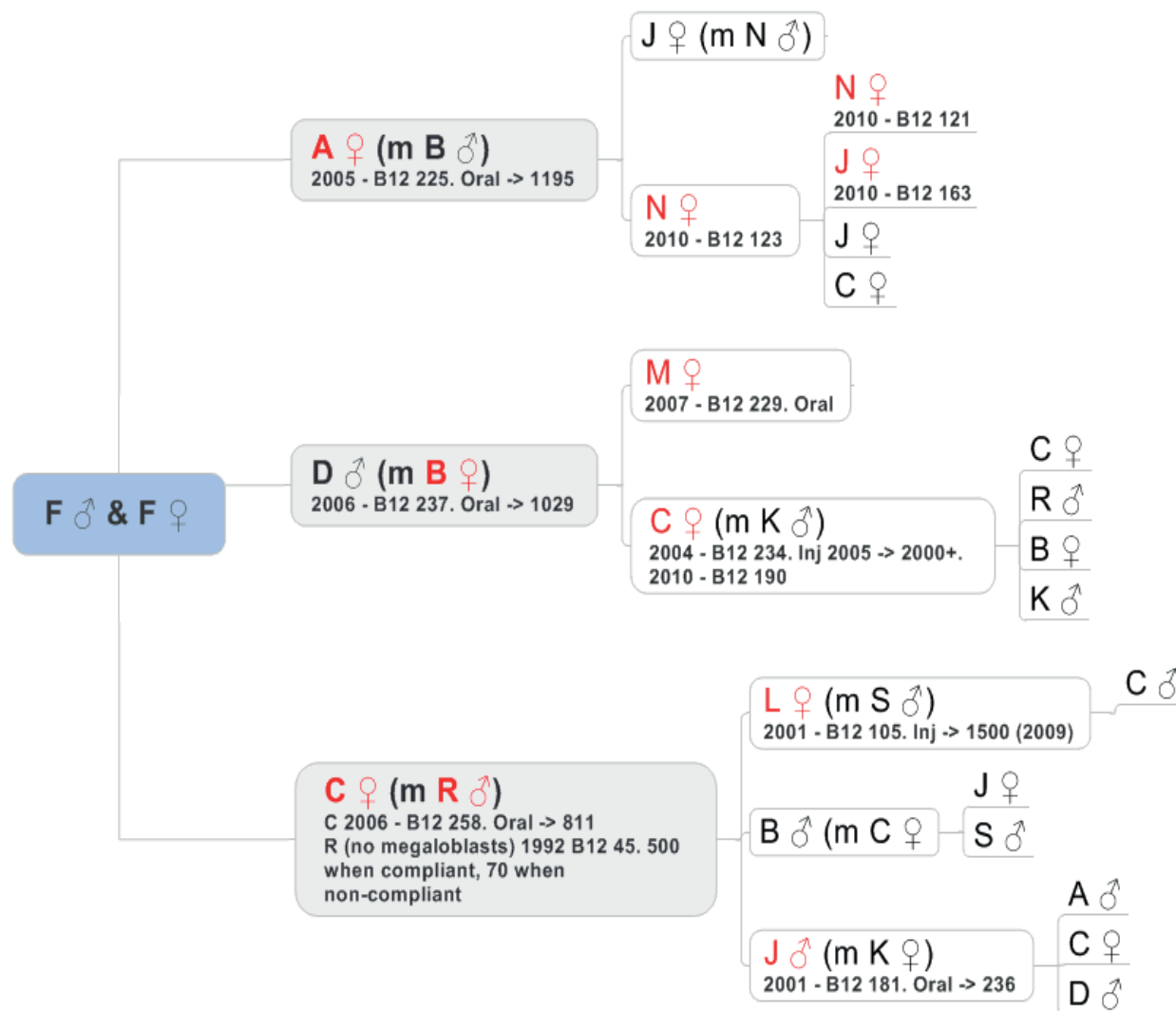
She came wanting another child but fatigued, fainting, no periods and no sign of getting pregnant. Blood tests showed low B12, so B12 replacement therapy was started (injections with loading dose and monthly or more frequent if requested).

Her periods returned within 3 months, also depression lifted and energy returned. Shortly after this she became pregnant and the child (now 2 yo) is developing extremely well – older sister (now 14 yo) was born missing a kidney and ureter, born prior to diagnosis of B12 deficiency.

# **Family Inheritance of B12 deficiency, B12 deficiency in children Case Studies**

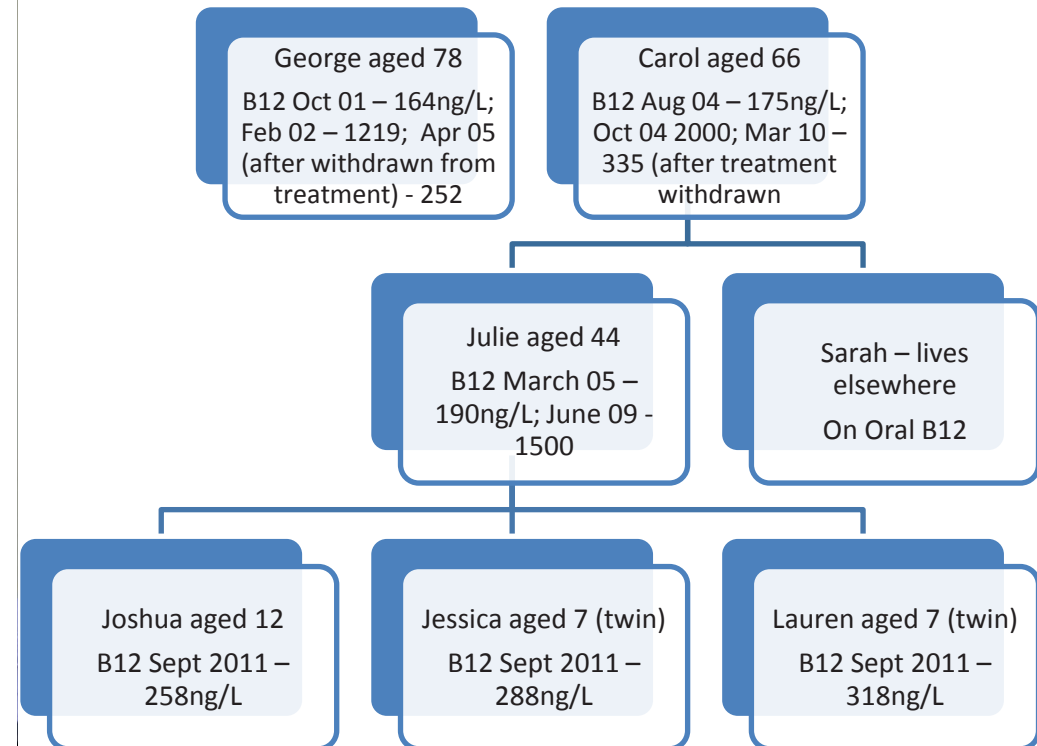
Including problems of folic acid supplementation  
without B12 in pregnancy

# Four Generations



- **RED** indicates known B12 deficiency
- Many young children (right hand side) haven't been tested
- B12 level at diagnosis and date – followed by treatment (>200ng/L = not permitted to inject)

# B12 deficiency: genetic incidence is clear

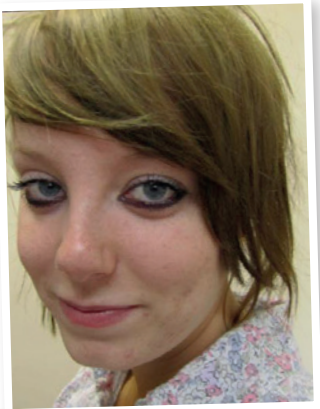
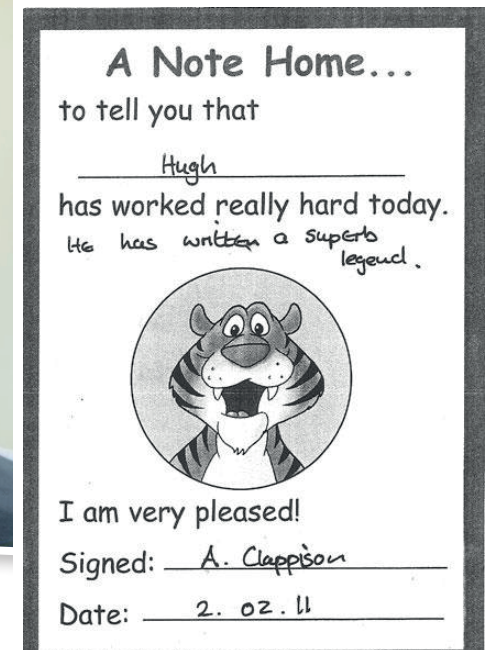


## Mother and children – Hugh aged 7, Louisa aged 13

Mother had a B12 level of 235ng/L in July 2005, falling to 178ng/L in Oct 2010 at which point she was given OC (oral) B12 and now has no signs and symptoms.

Son Hugh was performing badly at school, considered disruptive (?dispraxia?) – his B12 was 191 in Jan 2011.

Hugh commenced B12 replacement therapy and his work has improved rapidly (certificate of performance after 1 month of “loading dose” treatment).



Louisa (13) presented with depression, not able to cope with school work, refusing to go out with friends, and various other symptoms indicative of B12 deficiency. She was found to be B12 deficient (178ng/L – Oct 2010); following treatment, as you can see from the photo she is a different girl, back to her smiling sociable self.

This emphasises the likely genetic base for risk of developing B12 deficiency, and the benefits of early treatment.





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**B12 deficiency Support Group (B12d)**

**Charity Number 1146432  
Horden, Peterlee, Co Durham, UK**

**[www.b12d.org](http://www.b12d.org)**

**For more information,  
please email [notifications@b12d.org](mailto:notifications@b12d.org)**

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