

FAP Polyps Management

A family story of delaying Surgery in teenager with FAP for over 10 years

December 2018 update

By 2008 three of my four children were found to be carrying my mutation for Familial Adenomatous Polyposis (FAP).

We have managed to keep all three cases of FAP colonic polyp numbers down to a safe level for over ten years, and this is still on-going.

In March 2008, our eldest son at aged 14 years had a count of 100- 150 polyps before he began taking curcumin.

Over the ten years of use there has been a mix of increases and also reductions on polyps numbers but the eldest son age 25 in February 2019 he is now close to his original count of back in 2008 when age 14.

His two younger siblings then ages 12 and 13 in 2008 also began taking curcumin 2 years before their first colonoscopy in 2010

Naturally everyone wishes to know if curcumin actually works, and in our use we are confident to say it has worked for us not only in keeping numbers of polyps down, but also in this apparent reversing of polyp numbers. This can be observed clearly in 'Male 1' on the chart below whereby in 2012 his polyp numbers rose alarmingly whilst left on a low dose for 2 years. Clearly he had outgrown his low dose of 2g a day yet fortunately a dose of 8g (8000mg) of curcumin a day was strong enough to reverse the alarming polyp numbers from 300 to a new total of 100 in just 6 months. It was a remarkable test of curcumin's ability for there is no other explanation to why 200 polyps would disappear.

I hope the chart is helpful, and although polyp numbers seem to fluctuate a little due to different consultant's estimation, and when a spray dye is used the polyp seemingly to double numbers as many tiny polyps are revealed and counted.

The term pedunculated refers to a polyp on a stalk like a mushroom, whereas a sessile polyp is a low level round almost a button mushroom.

Below is a link to polyp descriptions to copy and paste

<https://www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-pathology-report/colon-pathology.html>

Male 1
Eldest Son

2008	100-150	x1 Removed	14	<i>Yellow curcumin</i> 2g –3g a day (divided into four doses)
2008 (9months later)	150	x7 biopsied	14	<i>Yellow curcumin</i> 2grammes a day. (500mg four times a day)
2010	50	all below 2mm	16	<i>Yellow curcumin</i> 2g a day (500mg four times a day)
2012	250-300	x200 pedunculated x 1 removed	18	<i>Yellow curcumin</i> 2g a day (500mg four times a day)
2012 (6 months later)	100	(numbers drop due to increase of curcumin dose over 6 months) x50 pedunculated	18	<i>Yellow curcumin</i> 8g a day (Divided 3g ; 2g ; 3g)
Spray-dye used from 2013	Spray-dye is used to reveal microadenomas that would otherwise not be seen in previous colonoscopies. The new comparison starts here.			
2013	200-300	(numbers increase under dye) zero pedunculated	19	<i>Yellow curcumin</i> 8g a day (3g; 2g; 3g)
2014	200+	zero pedunculated x4 removed	20	<i>white curcumin</i> 'C3 Reduct' (Tetrahydrocurcumoid THC) x5 400mg Reduct tablet equal potency of 7.5g of Yellow curcumin)
2015	100+	zero pedunculated few 5mm removed	21	<i>White curcumin</i> 'C3 Reduct' 8 Reduct tablets (3200mg) Equivalent potency of 12g of yellow curcumin Plus tried Alfa capsules 2g (x4 capsules) for 6 months
2016	200 +	Small adenomas none larger than 8mm non removed zero pedunculated	22	<i>White curcumin</i> 'C3 Reduct' 8 Reduct tablets a day Equivalent potency of 12g of yellow curcumin 1 tablet = 400mg
2017	200+	All 2mm-3mm Non removed	23	<i>White Curcumin</i> 'C3 Reduct (Tetrahydrocurcumin) 8 Reduct tablets a day
2018	150	only two 13mm sessile polyps removed in the descending colon	24	<i>White curcumin</i> 'C3 Reduct' (Tetrahydrocurcumin) 8 Reduct tablets a day. (two tablets four times a day)

Male 2
Youngest Son

Year	Polyp Numbers	Age	Dose used to gain result
2010	80-100 x1 pedunculated x 1 removed	15	1.5g a day (500mg three times a day)
2011	100 Biopsies taken	16	1.5g a day(500mg three times a day)
2012	100 x1 pedunculated removed	17	3g a day first 6 months then 6g a day
Spray-dye used from 2013	Spray-dye is used to reveal microadenomas that would otherwise not be seen in previous colonoscopies..		
2013	200-300 (<i>numbers increase under dye</i>) x 7 removed over 5mm	18	6g curcumin (2g three times a day) Plus 1g Alfa capsules (x1 twice a day)
2014	150 x 2 removed over 5mm	19	8g curcumin (2g four times a day) Plus 2g Alfa capsules (x1 four times a day for 10 months)
2015	150+ x5 reaching 1cm Increasing numbers of pedunculated up to 7mm	20	12g a day (3g four times a day) Plus 1g / 2g Alfa capsules (for a 8 month duration)
2016	No estimated numbers given Predominantly small flat polyps up to 6mm A few up to 8mm No pedunculated	21	White curcumin 'C3 Reduct' 10 x tablets a day Dose 2; 3; 3; 2 a day Potentially potency 15g of yellow curcumin 1 tablet = 400mg
2017	200 + Mostly small but an increasing number of polyps 9mm – 12mm in size 8 removed.	22	10 white 400mg (curcumin Reduct) & 4 x Yellow 1000mg tablets a day
2018	200+ Some flat polyps up to size 2cm in the transverse colon but still low grade dysplastic (cell changes)	23	10 white 400mg (curcumin Reduct) & 4 x Yellow 1000mg tablets a day

Female
Eldest Daughter

Year	Polyp Numbers	Age	Dose used to gain result
2010	50-60 Several biopsies taken	13	1g a day (500mg twice a day)
2011	50-55 x16 pedunculated removed	14	1g a day (500mg twice a day)
2012	40 4 biopsies taken Zero pedunculated	15	3-6g a day (1.5g- 3g twice a day)
Spray-dye used from 2013	Spray-dye is used to reveal microadenomas that would otherwise not be seen in previous colonoscopies. The new comparison starts here.		
2013	100 (<i>numbers double due to dye</i>) x 5 removed for biopsies x2 semi-pedunculated	16	6g a day (3g twice a day)
2014	150 x6 removed over 5mm Zero pedunculated	17	6g a day (3g twice a day)
2015	150+ x15 removed for the Radcliffe Bio Bank (research) Zero 1cm Zero pedunculated	18	6g a day (2g three times a day) Tried Alfa capsules x2 a day 1g for 6 months
2016	150+ The largest 8mm Zero pedunculated 10-15 removed	19	10g a day (10 tablets) doses 2g; 3g; 3g; 2g (1 tablet = 1g)
2017	200 + The largest polyp size is 5mm Non removed	20	first 6 months 8g a day of yellow & three 400mg white reduct next 9 months of 10g – 12g yellow (10 – 12 tablets)
2018	200+ similar to last year with one 6mm semi pedunculated removed	21	up to twelve 1,000mg tablets a day

Non steroid anti-inflammatory drugs 'NSAIDs'

Below I have included an image as a guide to sequence stages from an APC mutation to full colon carcinoma. A non Steroid anti-inflammatory drug (NSAIDs) is a label that can cover many medicines or compounds. Examples of NSAID's used in FAP research are sulindac, celecoxib , aspirin, Epa oil (alfa caps), and curcumin. There are research papers available which show how NSAID's affect the development of polyps in FAP if you wish to explore more technical understanding, but for simplicity I have marked on the image various stages the NSAIDs have been reported to have efficacy.

You will find my illustration is compatible to many scientific research images used.
Link examples

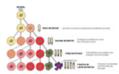
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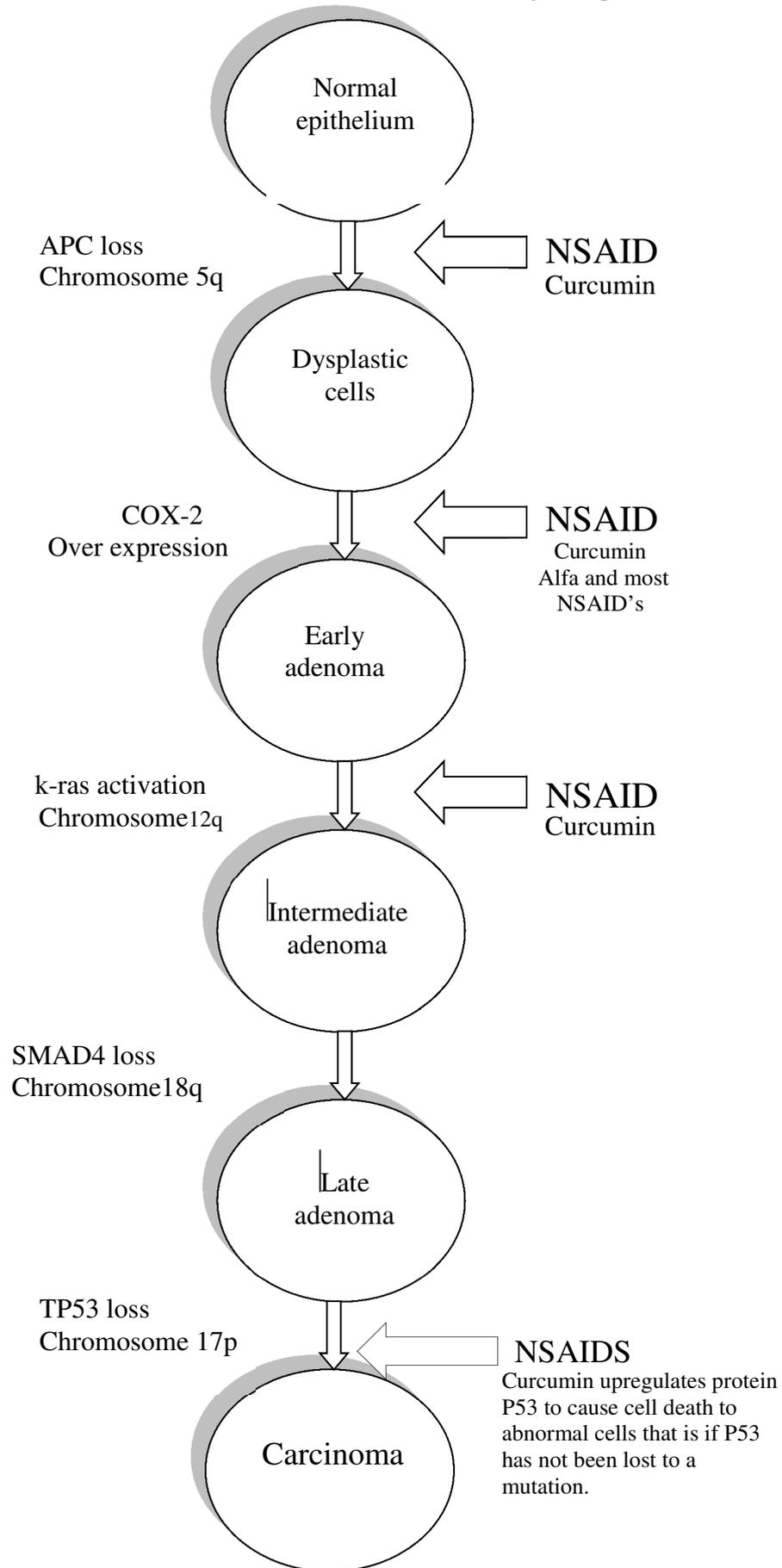
<http://www.scielo.br/img/revistas/ag/v42n2/a07fig02.gif>



<http://www.bu.edu/synapse/files/2011/01/cancerprogression.png>



NSAIDS (Non-steroidal anti-inflammatory drugs)



[More details](#)

Over the years the curcumin dose has been raised from a low dose of 1-2g in 2008, to doses of up to 16g a day in adjustment to an age related polyp increase. We have noted that from age 16 the polyps expression seem to increase dramatically needing a higher dose of curcumin of 8g a day by the age of 18years.

Over ten years of our curcumin use we have not only explored different dose amounts, but also have tried a combination of curcumin with EPA fish oil and a shift from yellow curcumin to the white curcumin tetrahydrocurcumin, (this being a more potent and in a smaller tablet form and it doesn't stain) yet they can cause some belly ache issue at first.

The curcumin and tetrahydrocurcumin we use is produced by Sabinsa.corp in their 'Sami Labs', Bangalore, India. To produce tetrahydrocurcumin the yellow curcumin goes through a longer extraction process for the compound to become white.

In the son who has a stronger polyp push expression we have tried combining curcumin with highly concentrated EPA fish oil called 'Alfa capsules' supplied by SLA Pharma from 2012 to 2015. The results had shown some promise, yet unfortunately the supply of Alfa Capsules became limited in supply preventing a fair evaluation of results.

Our daughter (youngest of the three) was introduced to curcumin at 11 years old and 10 months at 1g a day with negligible adverse effects. Her polyp count has remained stable at around 40-60 from 2010 to 2012, but under the spray dye colonoscopy in 2013 the numbers seem to have doubled. Yet we now realise this was due to the spray dye used which reveal microadenomas (small polyp hives) normally unseen with the naked eye without the dye. The spray dye allows consultants to gain insight of polyp development into the next 3 years or so, but for our yearly polyp comparison it became a little alarming at first when the polyp numbers appear to double in 2013 when the dye revealed micro polyp bumps to be included into the count previously unseen in other colonoscopies

There is no doubt curcumin has worked in suppressing polyp advance in our three children with FAP. with clear example I have already mentioned of effective reversing of polyps is in our eldest son back in 2010. To go into more detail, it was his stable condition in 2008 on a curcumin low dose the NHS decided his next surveillance could wait 2 years. In this period of time his polyps elevated from 150 to 300 (with 200 being pedunculated). This was a critical situation with so many pedunculated polyps (on stalks) Yet after raising the curcumin to 8g a day for 6months his polyp count reversed to only 100 with 50 pedunculated. This clearly confirmed curcumin had a leading effect on polyp expression, not only to hold back, but also reverse the polyp expression.

It has been in our observation there is no fixed family inherited expression, as each individual produce their own level of accelerated polyp development making it impossible to predict numbers for a fixed base dose per age. The FAP expression of polyps may be due to the persons own metabolic system as we have discovered between our two sons, whereas one will miss many doses due to night shift work yet his polyps seem to be very stable, whereas our second son is more careful with his dose taking, and even takes more per day yet has the most consistent concern of expression that is more problematic to manage.

The yellow curcumin has given us some good results over the years without health risks. The Tetrahydrocurcumin (white curcumin) has shown an equal effective method of management also more convenient in size and non-staining.

Alfa capsules we had hoped to take for a minimum of 3 years in combination of taking curcumin, but with supplies becoming a problem the experiment had to be terminated before we could get a clear picture.

Regarding curcumin side effects, in our experience, if a curcumin dose is introduced slowly at first, young teenagers can tolerate curcumin very well, even at high doses of 8g a day. The worst side effects are the looser stools, which may be resolved by eating an egg in the morning, and mild nausea or even stomach ache if taken on empty stomach - especially first thing in the morning. Yoghurt can greatly help with the stomach upsets.

White curcumin can be a little more difficult to tolerate due to its potency, but by introducing it very slowly over a longer period of time than yellow curcumin the dose can be acceptable, but unfortunately far more expensive to buy.

Alfa capsules (concentrated EPA fish oil) have not caused any negative reactions, but once again avoid them on an empty stomach as they can cause some nausea. Plus if you decide to bite the capsule, the epa oil can have a hot effect on the tongue due to the concentrated fish oil. In the UK these can be prescribed by a consultant.

Curcumin

The yellow curcumin we use is 'curcumin C3 complex' produced by Sabinsa.corp.

Sabinsa's Curcumin is sold under many known brand names like 'Dr Best'. You will not find Sabinsa as a labelled product, but if the curcumin states 'Bioperine' then this is their trade mark.

There is a list with the links listed on this site for suppliers, but as suppliers update their sites the links may become obsolete.

Tetrahydrocurcumin

Tetrahydrocurcumin (THC) we use is called 'C3 Reduct' and visually differs from standard curcumin by appearing white.

In human consumption within the digestive system, the standard curcumin whilst in the human intestine it is converted into tetrahydrocurcumin by E. Coli. Curcumin, also metabolized by other reductive enzymes in human body to become a tetrahydrocurcumin, and the resulting tetrahydrocurcumin is responsible for various activities associated with curcumin in the body. For example THC is far more bio-available, easier to be absorbed, and potent. Sabinsa.corp takes the standard curcumin through a further process to produce the THC as if in the human digestive system.

The potency of THC can make it more upsetting to the stomach. We have found taking two tablets (800mg) comfortable, but taking three in one dose (1,200mg) can evoke a feeling of needing to go to the toilet after 90 minutes, either due to just gas bloating, or a genuine need to go to the toilet.

We can only recommend the use of the Sabinsa product as it is produced to a high standard, absent of microbes, and delivering 95% active curcumoids from processed Asian spice turmeric. Standard turmeric on the shelf only delivers approximately 5-10 % active curcumoids.

It is worth a note; UK human clinical trials in Leicester use the Sabinsa product due to its many years of proven high quality.

Website Link <https://www.sabinsa.com/media-coverage/1013-india-made-turmeric-extract-gives-uk-cancer-patient-new-lease-of-life>



Website Link <https://www.sabinsa.com/products-from-sabinsa/127-curcumin-c3-complex>

Website Link <http://www.c3reduct.com/>

[Contact Sabinsa.corp https://www.sabinsa.com/contact-us/](https://www.sabinsa.com/contact-us/)

Alfa Capsules

Alfa capsules are a concentration of EPA fish oil produced at a high standard and supplied by SLA Pharma, available on prescription through a consultant.

Website Link <http://www.slapharma.com/>

More info of the clinical trial of Alfa EPA oil:

<http://www.clinicaltrials.gov/ct2/show/NCT00432913?term=S.L.A%2BPharma&rank=4>

We would like to thank the Oxford Genetic department for all their support and expertise in working with us to maintain a safe working practice in our personal exploration of curcumin& Alfa Capsules

An update will be in 12 months.

If anyone wishes to know more details, please contact Mick Mason who will forward my contact e mail mickmason@fapgene.com

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