

Appendix A: Full search strategies for journal literature.

PubMed

(hemochromatosis[Title/Abstract] OR haemochromatosis[Title/Abstract] OR C282Y[Title/Abstract]) AND ((“lifestyle factors”[Title/Abstract] AND iron[Title/Abstract]) OR (“clinical presentation”[Title/Abstract] AND symptoms[Title/Abstract]) OR (“maintenance phlebotomy”[Title/Abstract]) OR (“phlebotomy treatment”[Title/Abstract:~2] AND (iron[Title/Abstract] OR ferritin[Title/Abstract])) OR ((genetic[Title/Abstract] OR homozygous[Title/Abstract]) AND screening[Title/Abstract] AND HFE[Title/Abstract] AND (“iron overload”[Title/Abstract] OR “iron burden”[Title/Abstract])) OR “quality of life”[Title/Abstract] OR ((liver[Title/Abstract] OR hepatic[Title/Abstract]) AND (venesection[Title/Abstract] OR venesections[Title/Abstract])) OR “hepatic malignancy”[Title/Abstract] OR (arthritis[Title/Abstract] AND (HFE[Title/Abstract] OR C282Y[Title/Abstract] OR “iron overload”[Title/Abstract])) OR (pituitary[Title/Abstract] AND end-organ[Title/Abstract]) OR “iron removal”[Title/Abstract] OR (“hepatic fibrosis”[Title/Abstract] AND iron[Title/Abstract]))

Limited to English Language

568 results.

Ovid MEDLINE(R) ALL <1946 to July 25, 2023>

1	haemochromatosis.ti,ab.	1865
2	hemochromatosis.ti,ab.	6948
3	C282Y.ti,ab.	1602
4	((liver or hepatic) AND (venesection OR venesections)).ti,ab.	159
5	(lifestyle factors AND iron).ti,ab.	124
6	(clinical presentation AND symptoms).ti,ab.	17449
7	maintenance phlebotomy.ti,ab.	17
8	((phlebotomy adj2 treatment) AND (iron OR ferritin)).ti,ab.	111
9	((genetic OR homozygous) AND screening AND HFE AND (iron overload OR iron burden)).ti,ab.	139
10	quality of life.ti,ab.	371846
11	hepatic malignancy.ti,ab.	657
12	(arthritis AND (HFE OR C282Y OR iron overload)).ti,ab.	128
13	(pituitary AND end-organ).ti,ab.	115
14	iron removal.ti,ab.	405
15	(hepatic fibrosis AND iron).ti,ab.	305
16	1 OR 2 OR 3	8969

17 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 390824
 18 16 and 17 600
 19 limit 18 to english language 546

Embase <1974 to 2023 July 26>

1 haemochromatosis.ti,ab. 2409
 2 hemochromatosis.ti,ab. 8805
 3 C282Y.ti,ab. 2364
 4 ((liver or hepatic) and (venesection or venesections)).ti,ab. 276
 5 (lifestyle factors and iron).ti,ab. 156
 6 (clinical presentation and symptoms).ti,ab. 29745
 7 maintenance phlebotomy.ti,ab. 27
 8 ((phlebotomy adj2 treatment) and (iron or ferritin)).ti,ab. 167
 9 ((genetic or homozygous) and screening and HFE and (iron overload or iron burden)).ti,ab. 231
 10 quality of life.ti,ab. 583753
 11 hepatic malignancy.ti,ab. 1015
 12 (arthritis and (HFE or C282Y or iron overload)).ti,ab. 203
 13 (pituitary and end-organ).ti,ab. 151
 14 iron removal.ti,ab. 570
 15 (hepatic fibrosis and iron).ti,ab. 479
 16 1 or 2 or 3 11439
 17 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 615679
 18 16 and 17 953
 19 limit 18 to english language 872
 20 limit 19 to (article or article in press or editorial or erratum or letter or note or "preprint (unpublished, non-peer reviewed)" or "review") 539
 (Included the extra format limiter to try and avoid conference abstracts.)

Appendix B: list of websites searched for grey literature

National Grey Literature Collection funded by HEE: <https://allcatsrgrey.org.uk/wp/>

TripPro: <https://www.tripdatabase.com/Home>

International patient groups:

Haemochromatosis Organization: <https://www.haemochromatosis.org/>

European Federation of Associations of Patients with Haemochromatosis: www.efaph.eu

National groups:

American Hemochromatosis Society: <http://www.americanhs.org/>

Canadian Haemochromatosis Society: <https://www.toomuchiron.ca/>

Haemochromatosis UK: www.haemochromatosis.org.uk

Haemochromatosis Australia: <https://haemochromatosis.org.au/>

Irish Haemochromatosis Association: <https://haemochromatosis.ie/>